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**'Still There':**

**Mediating personhood, temporality, and care  
in London Alzheimer's Society support groups.**

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PhD Social Anthropology

The University of Edinburgh

2019

*Declaration*

I hereby declare that this thesis is my own work and has not been submitted for any other degree or professional qualification.

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DATE



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## ABSTRACT

This thesis is an investigation of the lives of people living with dementia and their families to explore how and why the 'social death' of the disease is mitigated through everyday practices of care. Findings are based on informal interviews and research done within London Alzheimer's Society services, in particular support groups for familial carers and support groups for people with dementia. One of the primary concerns of my interlocutors was keeping a person with dementia in temporal and spatial synchronicity with the rhythms and routines of family life. This was a challenge in the face of progressive dementia symptoms that disrupted people's ability to make sense of time and to navigate space. I show that staying 'in synchrony' is directly linked to constructions of relational embeddedness and independence, and is at the heart of familial care practices aimed at keeping a person with dementia 'still there.' My interlocutors' construction of personhood

relies on a delicate balance of interdependence in which connection to kin is encouraged, but also carefully negotiated so that autonomy is protected, and people do not lapse into explicit dependence. In the contexts of dementia, independence is a relationally constructed project, and relationality requires distinction and separation between people. I argue further that my interlocutors sought to maintain a person with dementia's personhood by finding ways for them to recognize and to reciprocate the care that they are given. In line with this, embodied forms of communication and behaviour previously considered 'odd' because they were inappropriate to the time and place came to be seen as meaningful. In my interlocutors' practices, we can see that care can be both constitutive of kinship and individuality, as well as a threat to it. Thus, my research is situated within anthropological studies that show the importance of both kinship and autonomy for Western personhood.

## **LAY SUMMARY**

This thesis is an investigation of the lives of people living with dementia and their families in order to explore the 'social death' of dementia. I show that great importance is placed on everyday practices of care. Findings are based on interviews and research done within London Alzheimer's Society services, in particular support groups for carers and also groups for people with dementia.

One of the primary concerns of the people I spoke with was keeping a person with dementia in sync with the rhythms and routines of family life. This is challenging because of the ways in which dementia disrupts the ability to make sense of time and to navigate space. Staying 'in synchrony' is directly linked to staying connected to family and friends and to keeping one's own identity, or personhood. Being able to do these two things were at the heart of family's care practices in which someone with dementia was considered to be 'still there.' My interlocutors' construction of personhood relies on a delicate balance of interdependence in which connection to kin is encouraged, but also carefully negotiated so that autonomy is protected, and people do not lapse into explicit dependence. In the contexts of dementia, independence is maintained in people's relationships with each other, and in their relationships people worked to maintain their distinction and separation from others. My interlocutors sought to maintain a person with dementia's personhood by finding ways for them to recognize and reciprocate the care they are given. Thus, embodied forms of communication and behaviour, previously considered 'odd' because they were inappropriate, came to be seen as meaningful. I show that in my interlocutors' practices, care can construct kinship and individuality, as well as threaten it. Thus, my research is situated within anthropological studies that show the importance of both kinship and autonomy for Western personhood.







## INTRODUCTION

*The man reached out and pushed a plate of biscuits toward my side of the table. Again. I had already eaten five overly sweet custard creams, but I reached for another with a smile and a thank you. He dipped his head, and I pushed the plate back towards him so he could take another himself. We sat, nibbling custard creams while the two women sitting to our right spoke to each other, recounting their past weeks, lamenting losses and taking stock of gains or, at the very least, assuring one another of a safe sameness. The women spoke of words forgotten, near-falls in the bath, days begun at 4 a.m. when the husband they had shared a bed with for decades left it for unknown destinations. They recounted the arrival of a hard-won disability-parking sticker in the mail, lunches eaten with family at noon, and a walk through a neighbourhood park hand-in-hand, the route going unquestioned and a swing set triggering memories of now-grown children. The man pushed the plate back towards me again, and I back to him, and we continued our custard cream exchange. Meanwhile, the woman to his right reached out to smooth down his sweater. He pushed the plate towards her, bumping its smooth white rim into the pale skin of her arm. She softly shrugged toward the other woman at a shared sense of forbearance, of living in a familiar room with a dimming lightbulb feeding growing shadows in the corners. Familiar*

*objects wink out from view at an incremental, unstoppable rate. These women, this man, make a life in the light there still is, occupying space they can still see.*

*The plate grows emptier. The woman to my left gathers papers into a neat pile. She half-turns in her seat to undrape the sweater hanging on the back of her chair, turning back to the group as her arm slides into soft fabric. The man's eyes follow this choreography of leaving, and he tries to stand, unsteady knees pushing back his chair. The woman to my right reaches up to lightly grasp his arm, saying, 'It isn't time to go home yet. We're staying to watch the music.' He looks to me, and I do my best to settle deeper into my chair, sinking down as I pick up a half-eaten biscuit. His knees bend as the now-sweatered woman stands, mimicking a pair of Willy Wonka's oompa-lumpas. But then, he quickly moves to stand with her, and the woman's hand on his arm becomes insistent. 'No, not yet' she says to him, then to her standing friend, 'It was lovely to chat, good luck this afternoon with all that, he'll feel better. Hopefully we can see you both next month'. Her friend nods, I offer a small farewell wave, and a passing look of confusion crosses the man's face. After the woman has walked away, the man's attention settles back on us who are left. I smile. 'Come,' his wife says, pushing the biscuits toward his standing legs. This time he seems to believe her, returning to join us in our waiting repose.*

\* \* \*

This scene from my fieldwork is not flashy or dramatic. It is a quiet depiction of everyday interactions that replayed countless times during the various Alzheimer's Society services I attended. Its characters, women, men, myself, played out our roles: wife, carers, person with dementia, husband, researcher, friend, and followed a dialogue with and beyond words. Our conversations were embodied and temporally framed. The man and I engaged in a rapport of biscuit exchange, synchronizing our moves in anticipation of a finished custard cream. The women were alternately narrator and audience to one another's stories, corroborating and sympathizing with trials endured and solutions forged. Under the current of these paired conversations, we spoke to everyone around the table with a hand on the arm, a small wave, and even with our stillness. We inhabited a shared space built on reciprocal communication with temporally grounded signals and conduct. Packing up was a closing of a conversation before a goodbye was said, a refusal of a biscuit would have spelled the same. But in this scene, some signifiers sometimes miss their mark. In the midst of conflicting signs of who is staying or going or whether an activity is ending or continuing, my friend, the man, was unsure about when he was meant to make his exit. He is reoriented with a soft

pull and a soft 'Come,' enticed with a biscuit. He is thus brought back into the fold of exchange, into sync with our communal wait for the next activity.

\* \* \*

This thesis explores the relationships and temporalities constructed and inhabited by people with dementia and their family members who help to care for them (referred to as carers). It draws on 17 months of fieldwork in south London, England, working closely with the Alzheimer's Society. The crux of this project is an investigation of how my interlocutors aimed to 'live well with dementia', a common refrain of the Alzheimer's Society and the UK's national dementia strategy (Department of Health 2009), by constructing practices of care in response to the cognitive, physical, and social challenges of dementia. The chapters that follow are informed by the fear, anguish, grief, courage, and love that I saw within these families as they came to terms with conflicting emotions and information about their own dementia or their family member's dementia. This thesis is a chronicle of the ways in which many carers and people with dementia strove to challenge and rewrite common portrayals of dementia as a tragic disease which 'robs' people of their memories and in which a person with dementia 'isn't really there anymore' or 'died before he's dead'. In such depictions, dementia is not only a decline of body and mind, but also of personhood. The

symptoms of dementia challenge a person with dementia's ability to 'manage on my own', maintain a position within their kinship network, and within a flow of normative temporality.

What emerges in this ethnography is that life with dementia illuminates the entanglement between autonomy and relationality, showing that both are necessary to the making of a person. It brings into sharp focus the importance of care and temporality to reckonings of personhood and relatedness. In the context of my research, 'good care' was temporally structured, in that the right kind of care was provided at the right time. It was motivated by a desire to maintain a person with dementia's personhood and 'there-ness' and strove to keep carers and people with dementia in sync with one another, and thus away from the brink of social isolation. I thus focus on practices of care that relate to helping people with dementia to stay anchored to normative reckonings of time, remember meaningful events, and anticipate future ones. I suggest that these abilities are taken as signifiers of relational embeddedness as well as a person's independence. Examining what kinds of temporally grounded care practices are chosen illuminates the significance of temporality to family life and constructions of autonomy. What becomes clear is that care is made meaningful to kinship when it is recognized and reciprocated by the cared-for person. Participating in good

care similarly allowed a person with dementia to remain 'socially alive' and 'still here' by staying temporally in sync with life around them and engaging in the relational 'back-and-forth' of familial life and showing that they 'can manage on their own'. This thesis challenges current ideas about what is counted as recognition in familial practices of care and dementia, and asserts that the navigation of temporalities is deeply implicated in conceptions of personhood.

This chapter provides a theoretical and contextual overview of this thesis. I present an overview of literature which has guided my approach and thinking, centred upon three main themes: the anthropology of aging and dementia, of kinship and care, and of time, temporality, and narrative. I then turn to a summary of my fieldsite and methodology. Lastly, I outline the chapters of my thesis.

### **Anthropology of Aging and Dementia**

My project is situated within larger discussions of anthropological and interdisciplinary research on aging and dementia. 'The old' have been defined both socially and biomedically as a distinct population with distinct perspectives and goals that overlap with ideas of illness. I examine how the occurrence of dementia affects the pursuit of 'the good life' in old age. In doing so, I present

contradictory work which positions dementia either as a particular kind of aging, as distinct from 'normal ageing,' or as somewhere in between. I give an overview of biomedical constructions of dementia and the medicalisation of senility in recognition of dementia as a biological and neurological condition that leads to physical death. As of 2017, it is recognised as the leading cause of death in England and Wales and accounted for 12.7% of all deaths registered (Office for National Statistics 2017). However, I also show how these biomedical definitions are limited and ambiguous, and do not satisfy the needs of my informants. I thus focus on works that position dementia as a 'social illness' (Kaufman 2006) because it affects the social network surrounding a person with dementia, and often makes the very experience of caregiving ambiguous (Sena and Gonçalves 2008). Within different contexts, dementia affects people with dementia and carers in contrasting ways, and garners different kinds of biosociality.

### *Anthropology of the Old*

Drawing from cross-cultural studies on aging, I define what is meant by 'the old', 'the aged' or 'elderly'. These terms are often used in common discourse as if their meanings were obvious, yet aging is a process as culturally informed as any other. The marriage of one's children, external signs of aging (greying hair, loss of teeth,



etc.), and a change in occupational status are, among other factors, noted as signifying a shift to 'old' (Fry 1980; Amoss and Harrell 1981:15). My findings, however, most closely mirror Kaufman's work on the 'ageless' self, in which a person's status and self-perception as 'old' is cemented by the onset of serious illness (Kaufman 1986), and being old can require new negotiations of one's autonomy and independence (Buch 2015). For my interlocutors, serious illness was indeed the most significant factor in defining what it meant to be 'old', and, as the illness at the heart of this thesis is one with serious cognitive consequences, being old with dementia created a unique nexus of difficulties that centred on being able to 'sort myself out'.

Amoss and Harrell differentiate the old into two groups they claim to be universal across cultures: those that are 'no longer fully productive economically' but of sound mind and body, and the 'incompetent aged' who require assistance with tasks of daily living (Amoss and Harrell 1981:3). These authors argue that the 'incompetent aged' are universally regarded as a burden, and thus choose not to delve into the intricacies of their status and ageing experience (Amoss and Harrell 1981:4). My research, however, addresses those whom they chose to ignore. I focus on the significant ways in which illness and aging are linked, and how the experience of dementia can complicate the experience of being old for 'the

incompetent aged,' as well as for their 'competently aged' relations. Notably, a person with dementia's status as 'dignified' and 'fully socialized' (Amoss and Harrell 1981:15) and their ability to remember or act appropriately is complicated as the disease progresses. These challenges lie at the heart of what carers and people with dementia strive for in their management of dementia, and are the focus of this thesis.

Beyond delineating the social definition of 'old', it is important to explore *for what* this population lives and strives. I frame my investigation as a response to Fry's question: 'What are the values which define the 'good life' in old age?' (Fry 1980:x). I argue that the maintenance of personhood is one of the major underpinning motivations of the types of care that caregivers and people with dementia enacted. I suggest that personhood is linked to common questions of whether a person with dementia is 'still there'. As such, an examination of personhood – how and why it is threatened by dementia and 'negligent care', and kept intact through 'good care' – is a focal point of this thesis. The motivation to maintain personhood is illustrated in studies of the 'social death' of elderly people and those with dementia (Kaufman 1994; Lamb 2014; Brannelly 2011; George 2010; Sweeting and Gilhooly 1997), in which people with dementia are often depicted as being 'lost' to their families or 'not there anymore'. In these depictions, 'there' is a signifier of

whether outsiders consider a person with dementia to still be a unique, aware individual. I show that this is at the heart of families' distress and grief, and people with dementia's feelings of isolation and powerlessness, and thus informs what 'good care' should accomplish.

It is important to note that while I often refer to personhood, other linked terms also surface in this thesis, such as 'identity', 'the self', 'status' and 'agency'. These concepts are not identical in meaning, nor do they possess singular definitive meanings unto themselves, but they do signal something understood to be intrinsically individual. I use this collection of terms because literature on the lives of elderly people, those with dementia, and carers in the West (Europe, the UK, North America) does so without clear uniformity. Further, I do so because the people with whom I worked do not use the term personhood, but did speak about 'still being there', about the importance of their identity based on biography or status as a carer or 'just another old person', about issues having to do with their own selves as opposed to others', and one's ability to 'manage things on my own'. While closely related, the subtle connotations of these terms offer a way to signal different attributes of a person and what is at risk of being lost to dementia, and what can be built and maintained in the face of it. I thus use the term personhood as an analytic tool to indicate a discussion of whether a person is considered 'still

there', and thus I position personhood as something that a person *has*, or – rather – *is seen to have*. It encompasses identity, a distinctive self separate from others, and an ability to act upon the circumstances of one's life – but as will be shown, personhood does not exist in a vacuum. It is socially denoted, granted, and constructed.

Tom Kitwood defines personhood as 'the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being' (Kitwood 1997:8). This description is apt because it is informed by dementia care contexts and underlines its social construction, thus situating my project as necessarily, though not only, a study of kinship. Attention to the person is 'key to describing the connection between relationships on the one hand, and values on the other' (Strathern 1997:7). Drawing from anthropological work on aging, I focus on the 'value' of decision-making, an expression of independence and dependence, as significant in the making of an older person's personhood (O'Conner and Purves 2009). I take this to be an element of agency, and thus position personhood in contrast to the 'social death' often associated with dementia (Sweeting and Gilhooly 1997; George 2010; Gillard and Higgs 2015; Watson 2015, 2016) to highlight the importance of agency in personhood. Fry explains that: 'To be independent is to be able to give and maintain a balance in

a relationship as one also takes' (Fry 1980:9). Fry quickly and astutely links independence to reciprocity, and shows the dangers of unbalanced reciprocity to a person's status. Through a separation of subjects, independence is made: one has to be a distinct subject, separated from the other, so that a relationship can be formed between them. Therefore, to have personhood is to be a *self* with a subjective point of view. When a person with dementia unbalances the reciprocity in their relationships by becoming too dependent as their cognitive abilities decline, their status as a separate, distinct self with intact personhood is threatened. Indeed, maintaining independence was often the goal of care strategies discussed in support groups and a loss of independence and ability to 'decide for myself' was a common fear among carers and people with dementia alike.

I also examine the 'passion[s] of aging' (Amoss and Harrell 1981:21) in an old age affected by dementia, and the factors that are critical to leading a 'good life'. Revisiting Fry's questions, I follow Clark's approach which 'offered compelling evidence for reframing aging as a *situated phenomenon*—an iterative, socially embedded process that requires adaptation to specific sociocultural contexts' (Perkinson and Somileo 2014:102, emphasis in original). In doing so, I assert that the values that define the 'good life' in old age do not differ greatly from those

prized in earlier adulthood. My interlocutors echoed other goals identified as universal in *Other Ways of Growing Old* (Amoss and Harrell 1981) such as physical and emotional security, respect from community, and a sense of usefulness to family and society. My work supports these findings: remaining in charge of one's own life and self-esteem were significant in the 'good lives' of older adults with whom I worked, and this was often achieved by remaining useful and positively embedded in one's surrounding social network.

The contexts in which people are living with and managing dementia offer unique insight into aspects of personhood which dementia is seen to threaten. I suggest that in looking at the experiences of the Londoners with whom I worked, we can also gain wider insight into what makes a person in English and Western contexts. I argue that, in my research context, qualities of autonomy and independence and also qualities of relationality and kinship are linked to the maintenance of personhood. This thesis is in conversation with anthropological work on personhood cross-culturally, particularly formulations of, and debates about, distinctions of persons as relational 'dividuals' versus separate individuals (Dumont 1980; Hess 2006; Ram 1994; Robbins 2002; Shweder and Bourne 1984; Strathern 1992). Englund and Leach have pointed out that 'current anthropological wisdom' is that 'all persons are both dividuals and individuals'

(2000:229). Indeed, my interlocutors' experiences of living with dementia demonstrate the entanglement between individuality and relationality in their conceptualisation of who counts as 'still there' as dementia progresses. I draw on Marilyn Strathern's work in English and Melanesian contexts in which she positions individuality as central to Western personhood in contrast to 'dividuality' in Melanesian constructions (1992). I do so because while I found both individuality and relationality to be part of people's ideas of personhood, autonomy and independence were nonetheless prevalent themes in my interlocutors' conversations and care practices, and words prominently displayed in Alzheimer's Society spaces. I also draw on Janet Carsten's appraisal of Strathern's work in which she proposes that relationality and kinship are more important than assumed in Western constructions of personhood, especially in contexts of kinship (2004). I suggest that dementia creates such circumstances in which the relationality of Western personhood is particularly apparent. In the following chapters, I will show that dementia blurs the distinctions between autonomous individuality and kinship. My work with people living with dementia and their carers shows that autonomy and relationality are both intrinsically implicated in what makes a person and that independence and kinship are mutually constitutive.

My ethnography among people with dementia and their relatives show that independence is a deeply relational construct. It indicates separation from others, but also is negotiated, allowed for, and made possible through families' care strategies to manage dementia. Further, while independence was heralded as the paramount goal of many such strategies, staying connected to kin and friends played an equally important part in people's lives and in being a person, being counted as 'still there'. Indeed, if others must witness one's personhood, staying embedded in a network of others is of ultimate importance. My interlocutors' experiences also indicate that personhood does not appear to be uniformly constructed between the genders. As the demographics section of this chapter will show, the vast majority of carers in my fieldsite were women, caring for men in their homes. More than half of male carers I spoke with took on more distant caring roles. They managed the actions of others, paid for things, and when faced with intimate care needs are often given more sympathy and congratulations in support groups than women. I thus draw on work suggesting that the personhood of women is more prominently founded in their relationality (Bowden 1997; Sherwin and Held 1993), drawing on historical associations of care, and familial responsibilities with women, in which women perform the intimate labours of raising children, preparing food, and sex in the home (Able and Nelson 1990; Day 2010; Bowlby et al. 1997; Boys 1990; Hochschild 1989; hooks 1991) in which 'the



mark of all laboring is that it leaves nothing behind' (Arendt 1998: 87). This thesis will unpack such gendered associations, addressing the fact that the majority of the carers I worked with were women. I illustrate the ways in which most of them were not content with a sense of identity, status, or agency founded in their relationality or role as carer, and worked very hard to not only secure avenues of independence for their person with dementia, but also for themselves. In this we see that carers and people with dementia alike sought to remain 'still there' despite the presence of dementia in their lives.

As carers and people with dementia grappled with maintaining the 'good life' and personhood, they contended with differing information about dementia itself, and in turn adapted and re-moulded their conceptualisations of what dementia is. I turn therefore to a discussion of biomedical framings of dementia to preface a discussion of how such framings were less straightforwardly helpful than one might think.

### *Biomedical Ambiguity*

Dementia, specifically the Alzheimer's type, was 'discovered' in the 20th century and its ambiguous entanglement with ideas of normal aging has since

complicated its validity as a disease (Scodellar and Pin 2013). Indeed, some in my fieldsites jokingly called Alzheimer's 'just a bit of old-timers!' None of the subtypes of dementia have final or succinct disease definitions so, for the purposes of this project, I use the broader term dementia to refer to the subtypes of diseases with which many of my informants were diagnosed. I do this because those who attended the Alzheimer's Society groups did not exclusively have the Alzheimer's type of dementia, and definitive diagnoses of dementia types cannot always be made with certainty. Further, the details of these diagnoses were not always clearly remembered or taken as fact by carers and people with dementia alike, a phenomenon that will be explored in greater detail in Chapter 1.

My project adds to the anthropological work on how dementia is entangled with contrasting ideas about what constitutes normal as opposed to pathological aging (Lock 2013; Kaufman 2006). Attention to the medicalisation of senility and ageing is pertinent because my research took place in London, an urban locality with access to specialised medical clinics and hospitals and the NHS, which has been noted for its focus on precision medicine (Day 2017) and biomedical evidence-based medicine. This medicalization is also pertinent because reports released by the Office for National Statistics have shown an increase in the number of deaths attributed to dementia in recent years. This has been linked to

a growing ageing population living longer after age 65, particularly men, governmental incentives for improved diagnosis of and reporting of dementia in clinics, and diagnostic coding updates within the NHS (Office for National Statistics 2017). Such shifts in statistical reporting of dementia signal greater, medicalised attention placed upon the old in the UK, and particularly on those seen as ageing pathologically. This illustrates how senility has moved away from being seen as a product of normal ageing to that of pathological disorder (Beach 1987; Fox 1989; Holstein 1997; Lock 2013). However, senility has also been described as problematic but not necessarily abnormal, whereas dementia is a biomedical definition of pathology (Leibing and Cohen 2006). Kaufman suggests that dementia is '[u]ttered today as a gloss for any neurological condition that slowly or rapidly destroys cognition, memory, reflexivity, and expressive capacity...' (Kaufman 2006: 24). In such renderings, dementia is ambiguous, and not a new or emerging disease, but instead a highly medicalised example of senility. These terms merge in uneven ways, however, when old age, senility, and dementia become conflated, making the borders of these terms ambiguous. This was reflected in the conflicting understandings of, and dialogues about, dementia which surfaced in my interlocutors' appointments with GPs, conversations with family and friends, and in their search for information about dementia.

My project uncovers how different people living with or caring for people with dementia interact with diverse dialogues about the diagnosis. That aging is 'situated' and an important developmental phase of life, means that analysis of the surroundings in which my informants live is crucial to understanding how '...dementia is a modern form of life itself...' (Kaufman 2006: 24), but not necessarily one which people who live with dementia feel is 'normal'. For the most part, analysis of my informants' experiences show that lay persons do position dementia as a process of pathological ageing, but that the majority do not rely on purely medicalised descriptions of senility. Many defined dementia through biomedical parameters such as a diagnosis, umbrella of symptoms, and a progression model. However, my interlocutors with dementia are more apt to normalise their dementia as 'just part of getting old'. Further, among both carers and people with dementia, mild dementia symptoms and worrying behaviours before an official diagnosis is made are characterised by uncertainty as to whether symptoms are normal or a sign of pathology (Chapter 2). Indeed, there tend to be grey areas of 'normality' that are attributed to mild stages of the disease.

The ambiguity of dementia extends from a history at the borders between normal and pathological ageing, to include ambiguous medical explanations of dementia pathology and diagnostics. In *The Alzheimer Conundrum: Entanglements of*

*Dementia and Aging*, Lock (2013) describes the landscape of current medical research into Alzheimer's. She discusses how a biological perspective on the disease powerfully shapes current understandings of Alzheimer's and dementia in European and North American contexts. The majority of research scientists with whom Lock worked held differing opinions about Alzheimer's pathology and causation (Visser et al. 2012; Lock 2013). European and American diagnostic guidelines hold that definitive diagnosis cannot be made until autopsy. Diagnosis is often linked to the existence of plaques or tau proteins, despite limited understanding of these markers, highlighting the importance the biomedical community places on identification of physiological changes in lieu of cognitive change for diagnosis. Further, diagnostic criteria for different dementias are frequently re-worked (Dubois et al. 2014; Morris et al. 2014) and can also include 'pre-clinical' dementia that does not include any cognitive markers. Unsurprisingly, these reworked diagnostic criteria are challenging for clinical practices (Wimo et al. 2014), which operate without the technology suite afforded by research environments, and also surface in public discourse about diagnosis (Devlin 2017; Jebelli 2017). Moving against the current of biologicalisation, Dubois et al. (2010) proposed a diagnosis criteria of Alzheimer's that incorporated biomarkers and memory loss, and removed the diagnostic authority of autopsy.

However this also serves to entrench the ambiguity of medical knowledge about dementia further.

This biomedical research context is part of the 'institutional milieu' (Leibing and Cohen 2006), in which dementia currently resides. Pressures direct dementia research to privilege certain perspectives despite what data might suggest is the best course of action (Pimplikar 2010). Subsequently, definitions of dementia are often shaped by biomedical research methods and demands of pharmacological funding. Dementia, and particularly Alzheimer's, patients become tools shaped to fit the requirements of pharmacological research (Dubois et al. 2010). Genetic tests are frequently performed in pharmaceutical trials despite many researchers explaining that carrying out genetic tests on individuals to predict the risk for late onset Alzheimer's Disease 'makes no sense at all' (Lock 2013: 164). In fact, despite claims of a 'genetic guarantee' in Alanna Shaikj's 2012 TED talk, a significant portion of those diagnosed with late onset Alzheimer's do not have the genetic marker that researchers search for, highlighting that 'genetic tests' for Alzheimer's are unlikely to provide reliable indicators of future risk, or be helpful in planning treatment or prevention (Lock 2006). Many medical practitioners argue that the persistence in genetic testing is 'almost certainly in part due to political expediency as far as funding goes' (Lock 2013: 172). Thus, biomedical

preoccupations with the biology and genetics of dementia, privileged by pharmaceutical funding, aim to push definitions of dementia, via diagnostic categories, toward greater medical clarity, but instead greater ambiguity is achieved.

While my project explores biomedical definitions of dementia in brief, I do so to understand how people redefine and disregard such biomedical constructions. Examinations of situations where people came together to discuss dementia specifically, show that in trying to understand what dementia is, people are able to find some meaning in biomedical renderings. However, in large part, they craft their understanding and expertise of the condition in the space between such biomedical information and experience. As such, my data adds to work on aging, senility, and dementia by lending insight into the ways in which carers and people with dementia come to use, question, or put aside ambiguous biomedical expertise about dementia to form their own knowledge and strategies. These are assembled through everyday dealings with dementia, and through the concerted efforts of support groups working together to find ways to 'live well with dementia' (a phrase prominent on much Alzheimer's Society promotional material) and attain the 'good life'.

My interlocutors' efforts to parse available biomedical information or decide its usefulness were not forged alone. Instead, 'making sense' of dementia was a social endeavour very much informed by peers' experiences. In line with this, I now turn to collectivities that formed via Alzheimer's Society services settings in which people affected by dementia come together to trade knowledge and help one another in which people affected by dementia come together to trade knowledge and help one another.

*Sociality of Dementia: making sense of ambiguity together*

Gusfield argues that '[i]llness is a social designation, by no means given in the nature of medical fact' (Gusfield 1967:180). Rabinow's concept of 'biosociality' (1996), will be useful to my investigation: he centres his concept on activism in relation to illness diagnosis, and on the contexts of emerging genetic understandings and new biological malleability, with which the ambiguity of dementia fits. However I do not embrace biosociality entirely, because many of the people I worked with feel uneasy about being strongly associated with dementia, and being labelled based on their role as a cared-for person or a carer. This uneasiness can be tied to the prevalence of caregiver burden and continuing stigma surrounding dementia.



Literature on the Alzheimer's caregiver burden is diverse in aims and research focus (Max et al. 1995; Cohen 1998; Donaldson et al. 1999; Fox et al. 1999; Andershed 2006; Werner et al. 2012; McGee and Myers 2014) but shows that dementia fundamentally affects family life through the stress created by the management and care of a person with dementia. Research also shows that the level of difficulty experienced is affected by carers' perception of dementia as a highly stigmatized illness indicating derangement, weakness, and old age (Leibling and Cohen 2006; Lock 2013; Werner and Heinik 2008; Werner et al. 2012; Donaldson and Burns 1999). While the 'biologization' of senility (Cohen 2003) has decreased the stigmatization of dementia along with the blame placed on people with dementia and their families for its causation (Mace and Rabins 1992), this stigmatization has still not entirely disappeared (Ballenger 2006; Scodellar and Pin 2013). Alzheimer's Society staff note that though they have seen a reduction in stigma, they believe that it still prevents many people from seeking care. It links to ambiguous understandings of ageing and dementia and explains why my informants are hesitant about strong associations to dementia and pursuing further organized efforts targeted at dementia.

Furthermore, the tightknit, intimate, and politically motivated connotations of Rabinow's biosociality are an imperfect fit for the social groups that formed among people who attended Alzheimer's Society services. Indeed, at a support group for people with dementia I attended, a clinical research coordinator from a nearby research hospital presented on dementia clinical trials in a partial effort to recruit participants. She left the day's meeting without collecting any contact information, and the people with dementia were clearly uninterested in participating, mentioning: 'well I suppose it might help our grandchildren – but there's not much hope for us, is there?'; 'I don't think I've got the right type [of dementia] for that'. Mentions in carer support groups of trials of dementia treatment or cure trials were often met by questions such as: 'what's the use of them [trials]?'. Clinical research was not at the heart of my interlocutors' concerns. This is in contrast to Rayna Rapp's work with families of children with Epidermolysis Bullosa (EB) who pooled knowledge about care for their children (Rapp 2003). Rapp found that the distress of families with children who suffered from EB caused them to create organized, motivated, financially-backed initiatives that pushed for research into underlying genetic causations of EB in line with efforts that arise from genomic research, as part of the new 'political economy of hope' (Novas 2001). My research is more closely aligned with that of Veena Das (2001) and of Elizabeth Roberts, which 'questions the relevance of applying the concept of

biosociality to every contemporary practice that involves emergent biological status' (Roberts 2007: 82). While these scholars find incongruence of the concept because their research sites significantly differ from the Western context upon which biosociality is based, I also find that the people in my Western fieldsite lack 'the capacity of a group to use social capital for dealing with biological conditions' (Das 2001: 2) in activist ways. Unlike the parents whom Rapp researched, my interlocutors, particularly carers, often discussed only having the time and energy to 'just get by,' and initiatives to push for research or reform were few and far between.

Thus, instead of biosociality, I focus on the 'working knowledge' created by my informants in Alzheimer's Society settings. Here, devising care strategies beyond biomedical understandings becomes key to establishing a sense of social connectedness, illustrated in oft-heard exclamations such as, 'It's so nice to meet people who understand! [the experience of dementia or caregiving]', as well as 'lay expertise' about dementia. Drawing on Mol's work, I position my informants' conversations about dementia and their strategies as a creative process of *tinkering* (Mol 2008). My interlocutors continually adjusted and repaired the arrangements in their lives to meet the ever-changing and emerging challenges wrought by dementia. In line with Lock's research (2013) and Margaret Clark's

pioneering work on the anthropology of aging (Clark and Anderson 1967), my project problematises the idea of 'expertise', taking seriously the negotiation of the ambiguity of dementia, the conceptualisations of dementia, and the lay methods of treatment and care which they constructed in place of, or alongside, 'recommended' advice from 'expert' clinicians and researchers.

It has been noted that 'most [caregivers] are resigned to the complexity of the situation' (Lock et al. 2007: 266) when speaking about biomedical renderings of dementia. However, my material does not show such resignation in all areas of their lives. Many people were proactive and creative in 'figuring out what to do'. My positioning of their efforts and strategies as 'lay expertise' is informed by Carsten's work on 'constitutive knowledge', in that I too am interested in 'what people *do* with the information they acquire and the different ways in which they may deploy it' (Carsten 2007a: 405, emphasis in original).

I also draw on Susan Lindee's concept of 'emotional knowledge' (2003, 2008) and Rayna Rapp's use of the same term (2003) to examine how group members pooled their working knowledge, day-to-day strategies, and emotional support, in order to craft short- and long-term strategies to keep people with dementia 'still there'. An investigation of the 'emotional knowledge' of dementia which my

interlocutors held, constructed, and shared, allows for insight into what aspects of dementia are most important to families and people affected by dementia. I propose that 'constitutive knowledge' and 'emotional knowledge' provide insight into what carers *do* with the varied information they encounter in different contexts of their lives, and how they assemble different forms of 'expert' and empirical understandings into '*working knowledge*' (Rapp 2003: 135, emphasis added). In examining the hopes and goals of my informants' working strategies to manage the everyday, I show that care is aimed at preserving people with dementia's dignity and ability to have a 'good life'. Biomedical knowledge became less important in constructions of 'hope' for the future. As the next section will discuss, people instead focused on ways to retain one's connection to kin and social networks as a way to 'live well with dementia'.

## **Kinship and Care**

In McKinley's reply to Schneider's 1972 *Critique of the Study of Kinship*, he writes that '...Western culture has no effective equivalent to kinship. What is taken for kinship in the West is merely a penumbra of bonds surrounding individual social life, with the value of individual autonomy always pushing such attachments very near to their vanishing point' (McKinley 2001: 138). This thesis in many ways is a counter-point to such a claim: the practices of care that animate my interlocutors'

lives not only demonstrate the pervading systems of kinship underpinning their lives, but also the importance of them. Further, while McKinley suggests that autonomy threatens attachments, this thesis will show that much of the care practised within families is centred on maintaining people's autonomy in order to *protect* relatedness.

The investigation of kinship in the context of dementia is principally informed by theoretical approaches which highlight the importance of care in everyday familial life (Patterson 2011; 2008). Care in the context of my research was a consistent, daily concern; family members crafted strategies to address the challenges a family member's dementia produced in their own lives and they called themselves 'carers'. People managing their own dementia discussed ways to 'support themselves', i.e. self-care and 'help my family manage too'. In line with my fieldwork observations, I use care to describe both *what* is done and *who* is doing it. Such practices and their enactors are necessarily reciprocal (Patterson 2011) and entwined with conceptualisations of care as a moral and ethical project concerned with what it means to be a 'good kinsperson' (Faubion 2001:12). As such, I also situate this thesis as an investigation of the 'ordinary ethics' (Lambek 2010) of my interlocutors' lives, as they navigate the unordinary terrain of dementia. As Lambek notes, these ethics are grounded in everyday practices and

are only rarely explicitly articulated when breaches are seen to occur. People's ethical discomfort at impinging on a person's freedom or 'leaving her alone' highlights the implicitness of these very practices of ethics and care.

Carework, particularly of an intimate nature, is often associated with the home (Day 2010) and mostly done by women, and thus seen as 'women's work' (Able and Nelson 1990; Bowlby et al. 1997; Boys 1990; Hochschild 1989; hooks 1991). This natural-ness of women as carers is a notion that, for the most part, went unquestioned by my interlocutors. The gender differences across my fieldsite have clear implications for an examination of care as a moral project of kin-making, in which providing care positions one as a 'good' kinsperson. I argue that it also provides further support for conceptualising care as a moral project in which care provisions is linked to being a 'good' wife or daughter, and illustrates how men who can provide intimate care for a person with dementia are reckoned to be extraordinary kin, as noted by people in support group and service settings. The gendered associations of care are noted also in other work on caring in dementia which highlight wives' ability to provide *interpretive caring* (Perry 2002), which rests on a wife's ability to draw inferences from a husband's behaviour in order to understand 'what would be meaningful or important to their husband' (2002: 311). This interpretive ability is connected to the importance of empathy in ordinary

ethics, and perhaps to moral projects of kinship. Antze, in his work on autism, proposes that 'the kind of empathy that matters morally, the kind we achieve by "reconstructing in our own minds the experience of another," to use Martha Nussbaum's phrase [2001: 331]...our failure to make intuitive sense of someone's behavior is not a prima facie basis for "objective" recourse to management or treatment...It can be taken just as readily as a call for the hard work of inference and imagination needed for access to a different experience of the world' (Antze 2010: 327). I argue that my interlocutors' practices of care can be seen as a response to this call, in that they resist a prima facie basis for finding a person with dementia as 'not there' based on strange behaviour and a seeming lack of reciprocal care.

The underlying questions for my discussion of kinship are: How is personhood linked to relatedness? Do care practices that keep someone related to other people, also help to maintain the personhood of those related people? Here I use the word 'someone' to highlight that 'being seen to be in one's family' is not only applied to people with dementia, but to their carers as well. I situate my research within larger discourses on the role of obligation, reciprocity, and memory in kinship to explore how a person with dementia's independence, and ultimately personhood, is made and unmade through care.



### *Relatedness through Obligation*

The presence of dementia demands acts of care from surrounding family members, but additionally complicates a person with dementia's ability to reciprocate this care. In exploring this paradox, I draw on and challenge the philosophical framing of an ethics of care (Patterson 2008) and kinship as a philosophy of moral obligation between kin (McKinley 2001). Care amongst kin has been framed as 'an indispensable part of moral life' (Tove 2008: x) and kinship has been positioned as 'an overarching philosophy of moral obligation' (McKinley 2001: 138) ) in which reciprocity is crucial (Pettersen and Hem 2011, Faubion 2001:10). These theories stand in opposition to descriptions of care as uni-directional and support my exploration of care as a moral project that compels us reciprocation in kind, in line with Bloch's (1971) argument that what makes kin reliable is that a moral force obligates care. This moral force provides a useful foundation upon which to consider what people's care *does* beyond its obligatory response to immediate needs. I argue that, through providing care, carers acknowledge their obligation to care for particular others, and thus mark out the recipient and themselves as kin.

I also consider the theme of obligation in response to Borneman's argument that '... [anthropology] has a responsibility...to examine critically and support in its normative frameworks diverse projects of caring and being cared for...[and] should instead privilege in analysis caring and being cared for as processes of non-coercive, voluntary affiliation...' (Borneman 2001: 31). My research explores who cares for whom, and how and why they do so, and challenge his description that caring and being cared for are inherently 'non coercive' or 'voluntary affiliation'. Yes, care is a process of affiliation, but it is also an *obligation* of kin-making and kinship. The following chapters address how family members do and do not care for their person with dementia, and vice versa. I argue that caring and being cared for are projects of both coercive and voluntary moral obligation, influenced by systems of relatedness preceding and resulting from the onset of dementia. A vast majority of carers took on this responsibility gladly and willingly, but positive associations and fulfilment gained through caring were also framed in sentiments of 'doing the right thing', or 'being a good daughter'. The positive ties of kinship can be powerfully compelling, and transformed by care.

In the context of my research, people marked out relatedness based on long-standing familial ties, and they marked shifts in that relatedness through acts of care. Borneman's finding in research on same sex relationships that care 'radically

rearranged social structure so as to invent alternative possibilities of affiliation' (Borneman 2001:40) nonetheless holds true in experiences of dementia. Changes in providing and receiving care often signalled and demarcated a change in the dynamic of relationships. What might have before been wife and husband, takes on new dimensions of carer and cared-for person with dementia. However, kin relationships did not disappear behind these new dimensions ushered in by the advent of care, because the onset of dementia did not introduce care into my interlocutors' relationships. Indeed, care appears to be a seemingly intrinsic component to the makings of kinship, and gendered associations of women as carers surface in conceptualisations through their roles as wives, mothers, and daughters. The following chapters also explore how my informants described their lives and 'who I am' through biographical accounts of the people for whom they have cared and by whom they have been cared. An attention to care was not new to people's views of their relationships, but with the arrival of dementia, the dynamics of care as a practice and mainstay of their relationships changed. Care comes to feature more prominently in relationships and what falls under the purview of care expands beyond what has been 'normal for a wife', or relationships prior to the emerging needs of dementia. This was evidenced in the uneven reactions that I witnessed to labels of 'carer', or resistance to 'turning into someone that has to be looked after all the time'. Prior forms of affiliations are re-

adjusted in the face of dementia, with differing levels of resignation, grief or nonchalance on the part of my interlocutors. As the following chapters will explore, people often sought to invent new forms of relationship dynamics that did not transmute into dynamics of straightforward dependency, in which one partner in the relationship held authority over the other.

While the advent of new forms of care and the tensions they created were clear, and will be explored in the following chapters, it is important to note that practices of care also served to foster relatedness. Care can be a powerful way in which families underscore the depth of kin relationships, in the face of threats, through their fulfilment of their obligation to 'relieve their burdens, hurt, or suffering' (Tove 2008:8). Some carers renewed their acts of care in response to being forgotten by their person with dementia, or called by the wrong name, aiming to reaffirm relatedness in ways that did not rest entirely on kinship 'laurels'. Relatedness came to rest on and be made anew in care and in the face of a breakdown of mutual recognition or memory of kin bonds, care can 'rearrange' affiliation to maintain bonds beyond pre-existing kinship labels.

Lending an economic framing onto degrees of relatedness and different family members' care contributions (Leach 1961:66), economic perspectives on care and

kinship call highlight that care is not only an abstract moral obligation to worry and emotionally care about a loved one's dementia. The practical fulfilment of this obligation has costs. Most hands-on caring is done informally and paid for by family and friends (Stommel et al. 1994; Max et al. 1995). Many of the carers in my field were retired spouses, most female, who devoted much of their daily lives and savings to the care of their partner with dementia. Many others were adult daughters who spoke of reducing their working hours to meet the caring demand of their parent's dementia. Care can be a significant financial and emotional sacrifice and investment.

#### *Personhood via Independence and Reciprocal Care*

Considering care as a component of kinship based on moral obligation and relatedness is also helpful in relation to the concept of personhood in this thesis. Here, I draw on Faubion's claim that '[t]he terms of kinship...qualify the self as a subject *through its relation to others*. Correlatively, they *qualify others to identify the self through their relation to it*...Though rarely individualizing, they label the self in its particularity, and specifically, in the particularity of its relations to particular others'. (Faubion 2001:12, emphasis in original). Faubion refers to 'the self', not to personhood explicitly, but he makes clear that it is being treated as

kin by another person which allows an individual to be a *somebody*: 'the self' as a distinct entity emerges through its position *in relation* to others. Janet Carsten notes that 'Close kin ties are intrinsic to the social constitution of persons', (2004: 83) and that relatedness matters even to a '[w]estern individualized person' even if theories of relatedness have been downplayed in previous analyses (Carsten 2004: 83). I suggest that a study of relatedness and personhood in the context of dementia allows for questions regarding *how distinct* a self might be. As dementia progresses, how a person with dementia is *in relation* to others may be analysed with respect to the degree to which 'they are the authors of their acts' (Strathern 1988: 142). The individual independence of their self, an important component of Western personhood, seems to blur as people with dementia become increasingly reliant on others for support.

Care charts the relations connecting people, but it is also a process in which subjects are made distinct from one another, while still embedded in an interdependent system of obligation. Care aims to sustain a person with dementia's distinct agency and independence, but in receiving care a person with dementia is marked as dependent. This paradox of a person with dementia's independence that is dependent on the care of others is a functioning, cyclical contradiction. By working to position the person with dementia as a distinct

subject who does not entirely recede into the role of one who is 'cared for', my informants seek to mitigate notions that their relative is diminished and 'doesn't care anymore'. Independence here is a socially embedded and constructed undertaking.

This cyclical nature of care highlights the importance of reciprocity, a relational activity of exchange, between kin (see chapters in Faubion 2001). Care as a conduit to relatedness must be bi-directional: to be kin is to care for the other and *to be cared for* in return. Reciprocity may become more difficult for people with dementia to render, and for families to recognize as coming from their person with dementia. Janelle Taylor's auto-ethnographical account of caring for her mother with Alzheimer's, illustrates the link between personhood and the recognition of care. Using Ricoeur's philosophical framework in *The Course of Recognition* (Ricoeur 2005), Taylor interprets subjectivity as requiring recognition by *an other* (Taylor 2008). Although recognition and reciprocity are not the same, I argue that recognition is a form of reciprocity. A subject's recognition of care being provided is also recognition that a reciprocal obligation of care is being established between themselves and the other. When relatives in my fieldwork felt that their person with dementia did not recognize their acts of care, they began to question whether their person with dementia still saw them as someone

related to them, a question which touched on their own sense of personhood (McKinley 2001:142). When people with dementia failed to recognize someone's care for them, the status of carers and of people with dementia as distinct subjects by virtue of being relationally embedded, was challenged. Their status as ethical, moral kinspeople became threatened, and carers felt guilty that they could not adequately provide what was needed, or even determine what was needed (Adren and Elmstahl 2008; Andershed 2006). The lack of reciprocity and recognition becomes a breach of the ordinary ethics of care.

### *Memory of Family Narrative*

Reciprocity of care must involve a narrative of the back and forth of care, obligated and fulfilled, for relatedness and kin relations between people to be meaningful. I engage with anthropological theory on the role of memory of family narrative in kinship to position care as an element of relational family histories constructed over time.

The concept of the 'interpretive labour of kinship' Carsten (2007) suggests that kinship is a process that is embedded in memory for the creation of meaningful connections between people. People are related to one another when they



remember how and why they have a kinship obligation (Antze and Lambek 1996). Problematically, a hallmark symptom of many dementias is memory-loss at basic levels, and in later stages there is often misremembering who kin are, their names and even their existence (Ball 2008; Callahan et al. 2009; Dubois et al. 2010; Fontana 1989). Taking Margalit's query, 'Is there an ethics of memory?...Are we obligated to remember people and events from the past?' (Margalit 2002:7) beyond the rhetorical, the ethics and process of kin must be remembered for memory to matter. Similarly, care must not only be rendered, recognised, and reciprocated, it must also be remembered and recalled for a person to fulfil their obligation. When families feel that this is not happening, then the narrative is disrupted and its meaning is weakened. This disruption threatens the stability of kinship ties based on shared memory, 'the cement that holds thick relations together' (Margalit 2002:7). In dementia, meaningful connections can be forgotten and care obligations left unfulfilled in the interpretive labour of kinship.

As my research was conducted among mostly English people, or at least among people who live in an English context, I draw on ethnographic work on kinship among people in U.K. contexts. Cannell showed that searching for the history of deceased relatives 'permits a deceased relative to be apprehended as a real person by their descendant – to become, as it were, actual rather than potential

family' (Cannell 2011:469). This relates to conceptualisations that a person with dementia is 'not there anymore,' and the efforts which families make to re-establish family histories in order to keep people with dementia 'actual' and 'real', and which echo Carsten's work on adopted people in Scotland. She found that '[b]ecause kinship and memory are seen as intrinsic sources of identity and the self, dislocations of kinship, and of a shared memory, may have a profound effect on a sense of self...a search for kin is one way of patching over an absence of memory' (Carsten 2007:90). To reverse this argument: while Carsten's adult adoptees searched for the birth kin whom they had never known, people in my field site similarly 'searched' for their kinsperson in their person with dementia, whom they had always known, as the person progressively forgot shared family histories. They searched by looking for signs of care being acknowledged and reciprocated, and recognitions of a shared family history. If personhood includes being anchored in knowing who kin are, then when this is lacking, so too is the completeness of that individual.

Lambek argues that self-identity becomes suspect when memory fails (Lambek 1996) and Kaufman (1986) shows that people establish their own identity through an iterative process, in that the person in question must indicate their identity. Therefore, both the act of remembering one's kinspeople, and iterating the

specifics of those relations are important in establishing one's own identity. To be a person, memory of one's personal narrative and relations must be kept intact, otherwise identity and personhood become suspect. Hence, the subjectivity of a person is recognized both through participation in, and memory of, the interpretive labour of kinship. The relevance of this interpretation can be seen in how the care strategies of many families involve not only enacting the moral obligation to care, but also working to maintain a person with dementia's ability to remain sufficiently 'in sync' with the family to reciprocate care and recall family narratives so that they could still be a person within that narrative. This is reminiscent of Day's work with sex workers in England whose lives are temporally divided, and who could not bring their past and future selves into the 'vivid present' (Day 2008). Similarly, people with dementia have difficulty recounting *narratives* of care and kinship, which demands an intact temporal grasp of how and when care has been rendered, and how and when to show care now and in the future.

### **Anthropology of Time, Temporality and Narrative**

The experience of time, its management, and the cognitive ability to understand it were recurrent concerns among carers and people with dementia. I discuss

narrative because this was the primary activity of support group meetings, and helped to form ideas about what normative experiences of time are, and are not. In this section, I draw on anthropological and philosophical work on time and temporality to define how these terms will be used in this thesis, to position my research within other work exploring these themes in contexts of old people and people with dementia, and finally, to examine links between narration and selfhood.

*What is time? What is temporality?*

To avoid relying on unclear, taken-for-granted meanings of time and temporality, I draw on analytical work that frames time and temporality as separate, if inherently connected, concepts. My usage of the term 'time' refers to what clocks measure (Ivey and Hume 1974), for a moment sidestepping a long and illustrious history of debate in the humanities on the nature of time. I use the term 'time' as my interlocutors use it, to refer to an important resource in their lives that is measured, 'spent', managed, and understood as a standardised entity. In this sense, an hour's duration passes at the same rate for everyone and is a measurement upon which everyone can rely. In contrast, I position temporality as that which occurs in time. It refers to a person's experience of, and relationship to,

time, and its social organisation and meanings (Zerubavel, Caldas and Berterö 2012). As exemplified in the experience of one carer, an afternoon spent caregiving seems 'to go on forever, but then I got an afternoon off to visit friends and it flew by!'. As such, I position time as a component of the relative experience of temporality. Time is 'not simply a mental ordering device, but an aspect of bodily involvement with the world' (Gosden 1994:7). Temporality is the particular rhythm of time through which people live.

Time refers not only to durations that a clock measures, but also to a sequential structure, which creates a linear ordering of past-present-future. This has clear narrative significance, which I discuss shortly, but first I underline that an understanding of time as linear implies that the past is that which has been experienced and has created the present, that present reality is an experience occurring now as a consequence of past events, and that the future is an imagined temporal terrain yet to be experienced. Time thus follows a unidirectional, causative path. Such a Newtonian concept of time as a distinct entity with a structure outside of human reckoning, has been opposed by Western philosophical approaches to time (Hegel 1970; Kant 1929; McTraggert 1908; Schopenhauer 1966), yet its rendering as linear seems to pervade even these critiques. Moreover, events are sequenced as *earlier than* and *later than* others (McTraggert 1908). In

short, we see an established view of time – either its perception or its absolute existence – described as sequential and linear regardless of whether time is real. Similarly, my contacts saw themselves as travellers on the ‘path’ of time: moving forward from the past, and ageing in the present until future death. My chapters move along this path too. I explore how such a highly structured view of time lays the groundwork for what is considered a normative temporal experience, which proves problematic to a person with dementia’s selfhood when they have trouble categorising experiences as past, present, or future, or before or after others.

### *Temporalities of the Old*

A literature review by Caldas and Berterö (2012) focusses on the practicalities of nursing elderly patients, and examines and differentiates the concepts of temporality and time, showing that they are part of the grounded mechanics of everyday caring. The authors employ Heidegger’s *Dasein* to elicit the subjective temporality of caring (particularly professional nursing), in addition to nurses’ necessary acknowledgment of objective ‘clock’ time. They propose that acknowledgement of patients’ temporalities, and a subsequent garnering of tolerance and patience for their different temporal perspectives, allows for better care through ‘being with’ the patient in the patient’s temporal reality. The significance in caregiving of ‘being with’ features in all of my chapters in different

ways. For example, many carers feel that they are the only ones able to provide the best care because they 'know' their person with dementia best from having spent the most time 'being with' them (Chapters 2, 3 and 4). 'Being with' is also significant for my underlying argument that at the heart of caregiving is a desire to find ways for people with dementia and carers to 'be with' one another within a shared temporality (Chapter 5), despite occupying different temporalities.

As with Caldas and Berterö's review, I found that care providers were encouraged to reconsider the authority of their own temporal perspective and 'acknowledge the patients' thoughts about their life (past), their disease (present), and their future' (Caldas and Berterö 2012: 249). I build on this work to show that acknowledgement was often pushed further to include agreement with people with dementia's perceptions and recollections of past, present, and future. In the chapters to follow, I unpick how families reconsidered how recollections were 'supposed to' be labelled as the past, the present, or the future, as well as the importance of the truth of recollections to personhood and identity.

Orona's work with caregivers of people with Alzheimer's (1990) links the temporal space of a carer who has a dyadic relationship with a person with dementia, to concerns about identity. While Orona's study was done in the United States in the

1980s, its site parallels features and findings of my own research context. Both are located in urban, Western, developed cities, and provide exposure to similar contemporary biomedical discourse, influences, and knowledge about dementia (Lock 2013). Orona shows that, over time, partners in relationships accumulate intimate knowledge about who one another *are*. 'gestures, nuances, and idiosyncracies of everyday living which tell me the other is who I perceive him/her to be, and which in turn, let me know he/she recognizes me' (Orona 1980:1251). I examine how conceptualisations of identity seem to rest on an assumption that how a person thinks and acts, their personality, is more or less a constant over time that is unearthed – not changed – through relationship. Identity here echoes 'a key stereotypical image...depicting the old as conservative, non-creative people who resist change' (Laslett 1984), in other words, temporally stagnant. My work reports on ways in which carers re-evaluate 'early indicators' of change that 'push[ed] against the negotiated boundaries of identity' (Orona 1980:1252) in working to make sense of both the past and the present (Chapters 2, 3).

I argue that when such boundaries change, then identity is threatened, and, in extreme cases, lost. Orona and I both show that families feel that they 'lose' people with dementia over time as their personality changes, though my work notes that 'negative' personality and behavioural changes spell a greater sense of loss than



'positive' ones. Examination of this theme will be explored in Chapters 2 and 4, in particular, and will show that people with dementia's personhood and connection to kin is not only threatened by a loss of memory, as discussed in the *Kinship and Care* section above, but also when they become disorientated to the temporal flow of family life and fail to do the right things at the right time. This is because 'the social construction of one's identity is a continual, life-long process in which maintenance and transformation occur in daily interactions' (Orona 1980:1251). This, however, does not describe the experience of all my informants. I build on Orona's work to show that, in some cases, carers and people with dementia build a new 'pool of knowledge' (Orona 1980:1251) in which they come to know one another – a new, changing other – over time, as dementia alters the 'idiosyncrasies of everyday living' (Chapter 5).

Hannah Arendt posits that '[e]ach human activity points to its proper location in the world' (1998:73). Discussions of 'doing the right thing at the right time' also necessitate a consideration of the way in which time and space are entangled and overlap (Munn 1992). My interlocutors' experiences show that temporalities are not untethered to space (and vice versa) and, in fact, that space is used to re-orientate people to time (and vice versa) when their behaviours and activities point to temporal and spatial disorientation. Further, examining what they

considered 'good' temporal rhythms of their daily lives provides insight into what they saw as the proper locations of their lives: the appropriate timing of activity is often tied to where the activity takes place. Further, 'where and when' in time and space refers not only refer to location in the quantifiable, objective sense, but as Haraway finds, also to a position within a network of locations. That is particularly significant for women, because existing in particular places is then an active, rather than passive, stance (1991).

Chapter 3 provides a closer examination of these themes and includes visual diagrams to illustrate this overlap of time and space, and the relational significances of being in particular locations at particular times. I use these diagrams to demonstrate time and space as an overlap of *place*, and importantly, to consider the significance of people's particular movements through relationally charged areas of their homes. Here, the literature on the importance of the home as both site of kinship (Carsten 2004, 2018) and of autonomy and independence for older people (Buch 2013, 2015) is important, because these spaces carry with them significant temporal qualities. In marking their 'proper location in the world' as in their own homes, carers and people with dementia also tethered the temporal flow of their lives to the procession of family activities within the home. Marking out their belonging to home was also linked to the sense that 'what I do

in my own home is my business'. In this, we see that their negotiations of the temporal and spatial qualities of their lives were animated by the tension of personhood in this context: remaining connected to and embedded within kin, but also retaining a sense of control and autonomy.

Finally, I draw on Hazan's work with a group of elderly Jewish people who make up the informal membership of a community centre in London. He found that they 'experienced three consecutive modes of socially constructed temporality' (Hazan 1984:574), including 'limbo'. We both find a helpful theoretical grounding in Turner's work on the 'liminoid' category (1977:47) and his 'paradigm of liminality' (1969:106-7) to describe how the old experience time. Hazan positions the aged as 'limbo people' who inhabit 'limbo' time wholly in the present, constructed through a disownment of the past, and a lack of attention given to a brief future, reinforcing my earlier discussion of time as a structure of past, present, and future. In Chapter 5 I compare the meetings of Singing for the Brain (SftB) with his findings, to show that SftB sessions similarly moved beyond linear structures of time through communication styles that did not require accurate references to, or grasps, on normative temporalities. I show that these singing sessions created a type of liminality, reminiscent of Turner's liminal spaces created

through ritual (1967, 1969, 1982) which created a '[l]ack of internal boundaries, inherent egalitarianism, sentiments of solidarity' (Hazan 1984: 575).

However, my ethnography diverges from Hazan's further inclusion of 'the abandonment of external ties' (Hazan 1984: 575). Hazan posits that the limbo of the older people with whom he worked is a response to isolation and a lack of social reciprocity with those outside the centre who are not 'old', and that they work to keep the centre separate from the outside world. In contrast, I show that SftB meetings attempt to remedy social isolation and broken ties between family members by bringing 'external' ties into the internal space of 'liminality'. These familial ties between attendees already existed 'externally' to the SftB meetings. My informants sought the liminality of SftB because it allowed for people of varying temporalities to meet one another in relations premised on affection, even love, not a temporality of normative, linear time. In Chapter 5's discussion on these themes, I also draw on connections to the work of Brijnath (2013) which touches on love in contexts of dementia (2013). My aim is to recognise the ways in which '[l]ove sustains relationships of mutual care within which children and adults cultivate their human capacities' (Day 2010: 292). I thus position my interlocutors' renegotiation of linear time, and celebration of the liminal space of SftB sessions, as practices of care aimed at maintaining personhood.

*Narrative: structuring temporality, making identity*

Kaufman (1986) shows that 'narrative thinking' is a pathway to understanding, performing, and constructing identity and meaning. I draw on this idea to investigate how certain narrative structures shape the meanings of dementia, personhood, kin, and time for my contacts. Further, in discussions on 'making the self' through narrative, the importance of memory is often evoked. I address how a disease which pathologically and pervasively disrupts a person's ability to remember in 'normal' ways, pushes them and their carers to construct new kinds of narratives.

Geertz positions ethnography as a project of recounting others' stories and narratives, and, in this respect, this thesis is ethnography of ethnography. The discussions in support groups mirror James Clifford's description of ethnography as 'emplotted by powerful stories' that 'describe real cultural events and make additional, moral, ideological, and even cosmological statements' (Clifford 1986: 98). Applying the term 'cultural' to events in the microcosm of everyday life, the method of sharing 'powerful stories' and analysing these stories for 'additional statements' is common practice in support groups. They can be seen as a project

of lay ethnography in which carers and people with dementia use narrative to make sense of their lives affected by dementia, in a vein that mirrors Kleinman's 'illness narratives' (Kleinman 1989) or Glaser and Strauss's 'illness trajectory' (Strauss et al. 1985). The powerful stories being told in these groups '...enmeshes the disease in a web of meanings that make sense only in the context of a particular life' (Kleinman 1988: 96). They also 'refer not only to the physiological unfolding of a patient's disease but to the *total organization of work* done over that course, plus the *impact* on those involved with that work and its organization' (Strauss et al. 1985: 8, original emphasis). Thus, support groups meetings are an ongoing, collective ethnographic project of illness 'narrativization.' Experiences are analysed for insight on how to 'live well with dementia,' 'aris[ing] out of a desire to have life display coherence, integrity, fullness, and closure' (Becker 1997: 12).

Narratives that describe the internal experience of events, bring narrators and audience together into shared meanings about these events (Bruner 1990; Hank 1993; Miller et al. 1990; Ochs 1996). Ochs and Capp summarise that '[s]ingly, each plot attempts to illuminate an experience. Pieced together over time, narrative plots attempt to illuminate a life' (Ochs and Capps 1996:8). Plot and narrative, laid out in this way, touch on group members' comments that support group

meetings help members to make sense of the experiences of themselves and others. Group members' lives are illuminated through the narrative process of meetings which create shared, local understandings of common experiences in caring or living with dementia. Group settings allow for an appreciation of both the experiential significance of an afternoon spent at lunch with friends instead of caring, or forgetting a doctor's appointment. A collective identity is forged in groups as common 'rites of passage' are experienced and shared by members, such as a carer's first experience of having to find a wandering father, for example, or a person with dementia's embarrassment at forgetting a family members' name (Graham 1994; Harris 1989; Stromberg 1990). Lives also seem to 'make sense' when they can be told, narrated, and 'sorted out' into normative structures that fit in with how others recount their lives in the group.

The narrative structures which carers and people with dementia use to make sense of their experiences and craft useful care strategies also shape the temporal experience of dementia. 'Personal narrative simultaneously is born out of experience and gives shape to experience' (Ochs and Capps 1996), echoing Hazan's work on how stories and social organisation shape and emerge from each other (Hazan 1984). Similarly, Cohen and Leibling (1994) argue that group and individual stories can inform one another by internalisation and projection.

Narrative often positions narrator, characters, and audience in relation to past, present, and future recounted events (Guignon 1993; Heidegger 1962), and relays future and present concerns (Goodwin 1990; Ochs 1994). This often occurred in support group discussions. Indeed, as I discuss in Chapters 1 and 5, carers, in particular, and to a lesser extent people with dementia, learned an expected trajectory of dementia progression and the caregiving journey by comparing and contrasting their experiences with others' narratives.

However, the 'illumination' of life based on normative plot and narrative is at the heart of the challenges faced by people with dementia face as their condition progresses. Indeed, 'losing the plot' was evoked often by people with dementia and carers to describe dementia consciousness and increasing difficulties with memory. 'Losing the plot' also has other significant ramifications, beyond the identifiers such as gestures or idiosyncrasies, and autobiographical narration is important to the construction of identity and personhood (Broomier and Harbaugh 2001; Dennett 1988, 1989; Flanagan 1996; MacIntyre 1981; Schechtman 1996; Taylor 1991). Like other work on biographical narrative, I frame my informants' experiences as happening within 'a context in which it is impossible "to tell your story right," or to tell it at all, [and illustrate how] it becomes possible to see how biographical conventions privilege memories of continuity over time



that lead us to look back retrospectively on the integration we have achieved' (Day 2008: 190). These biographical difficulties create a unique set of circumstances for my interlocutors' personhood when one considers that '[n]arrative is radical, creating us at the very moment it is being created' (Morrison 1994:22). Work on identity and narrative argues that this is a fluid process, in which identity is not necessarily static (Lifton 1993). However, as discussed earlier, when faced with markers of a changing personality, families often question the continuity of a person with dementia's personhood.

The historical and sequential accuracy of narration and autobiography is an important element of identity constructing narrative (Spence 1982). Many of my contacts responded to this conundrum by choosing narrative truth, i.e. the creative project of coherent identity, to take precedence over historical truth. This care strategy works to maintain personhood despite a person with dementia's difficulty in 'keeping track of the facts'. However, if the person cannot recount a tale that draws on a past event because they cannot remember it (or remember it accurately), but then also lack the *cognition* to piece these tales together – how then are people with dementia meant to achieve the illumination narrative promises? How 'true' is narrative?

The entire premise of narrativity as an organising feature of lived experience – and importantly selfhood – is challenged by philosopher Galen Strawson (Strawson 2004). I situate my work within this debate because many of my contacts' narratives and experiences became progressively more 'episodic' (Strawson 2004), and less sequential. Strawson argues that there is a widely accepted notion that human beings 'typically see or live or experience their lives as a narrative or story of some sort' and this 'is a good thing; a richly Narrative outlook is essential to a well-lived life, to true or full personhood' (Strawson 2014:428). He states, 'It's just not true that there is only one good way for human beings to experience their being in time. There are deeply non-Narrative people and there are good ways to live that are deeply non-Narrative' (Strawson 2014: 249). Strawson is not the only critic of the precedence of narrativity; Christman suggests that 'narrativity is a misleading and, in some ways of understanding it, implausible condition of what it is that adds unity to personhood and personality' (Christman 2004: 695). He instead favours interpretive reflection of one's life as significant to personhood.

Strawson's opposing approach to the concept of narrative couples *time* with *narrativity*. Dementia can simultaneously attack people with dementia's cognitive ability to sequence events, understand the concept of time, recall the vocabulary to tell a story, form words verbally, enact stories 'charade-style', and write.

However, through certain acts of care, they are persons who continue to exist over a passage of time. I use the word *exist* to recall earlier discussions of the way in which people with dementia can be described as 'not there' or having 'died before he was dead'. I point to the contentiousness of the statement that people with advanced dementia still *experience* the passage of time. I thus position my research as an investigation between two extremes: at one end, how people with dementia progressively merely exist in time, and at the other, how people with dementia continue to experience the world around them, regardless of dementia's effects. In this later contingency, dementia has only challenged people with dementia's ability to articulate a continuing narrative life or, more drastically, that narrativity is not a prerequisite to 'experience being in time'. Holding this view motivates carers to maintain a person with dementia's personhood past a point in time where primary carers' other family members say that 'he doesn't know what's happening anymore'. Keeping a person with dementia anchored in time through normative temporal routines, or rewriting what counts as 'doing the right things at the right time', is not straightforward or singularly pursued. The chapters that follow are an examination of how people with whom I worked vacillated between keeping to traditional, normative reckonings of time, and moving past them to forge new conceptualisations. I thus align my project with Hazan's call for '[a]n anthropology of temporality [that] would view time not just as a conceptual

codification of change, but as an independent variable, a generator of relationships, at the same level as other extensively investigated social phenomena' (1984: 575).

## **Fieldwork**

I completed seventeen months of fieldwork from October 2014 to January 2016, across four south London boroughs (Local Authorities) varying in socioeconomic and demographic make-up. The exact boroughs will be kept confidential as agreed with my interlocutors and the Alzheimer's Society Research Ethics Board. While my ethnography is centred on an examination of dementia, the contexts of my research were non-clinical, and I worked closely with people with dementia, their familial carers, and Alzheimer's Society staff, and conducted interviews in their homes, and in cafés. I spent most of my time as a volunteer in service settings attended by carers and people with dementia, organized by Alzheimer's Society staff, and paid for by Local Authorities or funding from private companies. Services included support groups for carers, support groups for people with dementia, 'Caring Cafés', 'Supper Clubs', and 'Singing for the Brain' groups, which are described in further detail below.

As a volunteer, I was in consistent and direct contact with service users and staff, often while wearing a name badge with LILIAN written in clear, block lettering. I observed the collaborative working style of Alzheimer's Society staff and the dynamics of the more fluid services, which operated outside the set structure of support groups and interviews. My tandem role as researcher was not made obvious by my appearance, except perhaps for my ever-present notebook and pen, however, I explained my role as a PhD researcher to attendees often, was introduced as such by staff members regularly, and many people asked after my studies regularly.

In support groups my role was clearly defined: I helped as volunteer before and after, and was almost always silent during meetings while I fastidiously copied down transcripts of the discussions. My role as researcher was explained at the start of each group, and group members' were asked permission to allow me to sit in on the group and take research notes of the session. It is from these notes, that I draw much of my analysis of how my contacts manage dementia in their daily lives and construct care strategies.

The significance of temporality and personhood apparent in support groups was explored more deeply in one-on-one interviews with carers and people with dementia. I carried out a total of 32 informal interviews with carers, people with

dementia, and Alzheimer's Society staff members and was told numerous times that they were 'so glad' I was doing research on their experiences of dementia, and 'ways to cope'. Modelled on an illness narrative framework using broad prompts, I aimed to withhold my own sense of dementia progression from my interviewees. Conversations lasted up to three and a half hours, and most were intimate and emotionally charged. The people with whom I worked had deep reservoirs of experience related to their reckonings with dementia, and interviews often ended with a mutual recognition of exhaustion.

### *A note on terms*

I have endeavoured to be careful in my use of language, in consideration of a long history of stigma associated with dementia and continuing depictions of dementia as an 'epidemic.' In line with research and recommendations compiled by DEEP (Dementia Engagement and Empowerment Project)<sup>1</sup> as well as my own insights gained from working in dementia contexts professionally and academically, I use the terms 'person with dementia' 'person living with dementia' or 'interlocutor

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<sup>1</sup> DEEP is a self-governing UK network composed of around 100 groups of people with dementia. It a 'rights-based' network which 'encourages groups to identify and speak out about the issues that are important to *them* (not only to be 'consulted' about issues that are important to *others*). DEEP produces guides aimed at organisations about good practice concerning involving people with dementia. <https://www.dementiavoices.org.uk/>

with dementia' to refer to those with whom I worked. I use 'carer' to mean those who took on major caring responsibilities for a person living with dementia, and who in my research were mostly family members. I use this term because it is used by my informants, and is prominent in Alzheimer's Society material as well in U.K. government legislation. When I use the term 'interlocutors', 'informants' or 'people with whom I worked' without any qualifiers, I am referring to both carers and people with dementia.

### *Demographics*

A few services met in a borough well-served by transportation links, with high-end shops and a large range of established chains stops and boutique restaurants. Mostly wealthy, upper and middle-class, White English carers attended this group, and the majority lived with their people with dementia in large flats or homes that they owned. They had or had had successful careers based in London in areas such as law or finance. Another borough I visited was on the outskirts of London and solidly middle class. It was served by a single tube line and was residential, with detached homes and smaller blocks of flats and larger main supermarkets with dedicated parking lots being more common. Contacts from these areas were mostly white British, with a few people with dementia and carers of South Asian

background. Many of the carers and people with dementia who lived there owned a car as their primary mode of transportation. The other two boroughs were on the lower end of the socio-economic scale and more urban than the others. Main streets comprised small businesses such as corner grocery stores and nail salons. The carers and people with dementia who I worked with were working to middle class and from white English, Black English, South Asian, Afro-Caribbean, and Irish backgrounds (in order of prevalence). These areas were well-serviced by tube and bus lines and bustling, diverse foot traffic was common. Many residents lived in multi-storey buildings or council house developments, with a few of my interlocutors living in homes in suburban areas. Volunteers and Alzheimer's Society staff across all boroughs were, by majority, White women, with a few men and a few Black British women.

Gender distributions offer interesting insight into the gendered nature of care. The gender distribution of *attendees* at the social person with dementia/carer mixed settings of Caring Cafés, Supper Clubs, and Singing for the Brain groups, was mostly even. However, most male people with dementia attended with their spouses while most female people with dementia attendees came with a child (usually daughter) or attended by themselves. It was notable that gender biases also surfaced across person with dementia/carer lines in all groups, except for



person with dementia support groups: on average, female carers outnumbered male carers eight to one. Half of male carers lived with their person with dementia, whereas almost all female carers did. In contrast, person with dementia support groups were usually attended with a 60/40, female/male ratio. Most men in the persons with dementia support groups lived with their female spouses, from whom they received car rides to the support group. In contrast, only three women received lifts in a car from a carer, the majority of women making their way to the support group independently and half of these women lived alone.

This gender disparity was rarely identified as noteworthy by older carers and people with dementia at Alzheimer's Society services I attended. The only direct conversation I recorded was in a carer support group in which a group of women wondered, 'how are all the old ladies who've dementia managing? You don't see men coming along to these [support] groups', suggesting that 'talking like this would be too hard for men'. In response to my question about 'where all the women with dementia are,' I was told that when mothers or wives get dementia and it's up to the husband, or son, she'll usually go into a home or into care. I don't think people really expect men to take that on'. Only female children carers aged under 45 hinted at a sense of dissatisfaction with how care-work had been distributed in their family, mentioning that they were expected 'to do most of it,

like it's easier for me'. Accordingly, the majority of male carers under the age of 60 mentioned sharing their caring tasks with a female family member. These gender distributions inform the contexts of care that arise in my fieldsite. The following chapters will touch on its effects on how carers conceptualise carer burden in relation to identity, moral framings of care, and how my informants crafted particular carer roles and strategies in alignment with gendered notions of personhood.

## **Service Types**

The services outlined below were not offered within each borough but most boroughs offered at least a Caring Café and a support group for carers. Service types operated similarly across boroughs, but each had its own character created by the unique intersection of people who attended, volunteered at, and organised these services, as well as local offices' aims and funding stipulations. Over the course of my fieldwork, in reaction to financial and bureaucratic variables, one borough established a new support group for people with dementia, the location of two long-standing services was changed, and the set-up of two different Caring Cafés was changed to fit the new desired outputs of new funding contracts. Many of these changes were indicative of a trend from funding bodies wanting to

reformulate services' primary function as a source of information, as opposed to respite.

### *Support Groups*

I regularly attended 4 dedicated support groups for carers, which met every 2 weeks, or once a month, and regularly attended 2 support groups for people with dementia which met every two weeks. These support groups were held in private rooms at community centres, churches, or carer centres. Most rooms were cozy, with soft seating and boxes of tissues, while others were more functional. All groups organized chairs into a circle or square, and doors were kept closed. Notably, support groups were held in separate spaces: people with dementia were not allowed to attend carers groups and vice versa, a divide explicitly refereed by staff and volunteers. Support groups for carers met monthly for hour-long sessions during a Caring Café or as a stand-alone activity on weekday afternoons or evenings, and were usually attended by three to twelve people. Support groups for people with dementia were held on weekday mornings for two hours and most met twice a month, with consistent attendance by established members. The longer running group usually had at least ten people with dementia, and a newly formed support group was usually attended by three or four people. The dynamics and social norms of these different groups are explored in Chapter 1.

### *Caring Cafés*

Over the course of my research, I volunteered at 3 different Caring Cafes, which usually met once a month. These 'Cafés' were a social affair for people with dementia and carers alike, and followed a structured temporal flow. Attendees arrived at reception and signed in while volunteers settled carers and people with dementia into seats and fetched tea and coffee. People sat at tables set with 'conversation starter' pamphlets and chatted, while a light buffet style lunch was served. An hour of games and craft activities followed, which coincided with the carers support group, run in a separate room, which I also sat in on 80% of the time. Volunteers and Alzheimer's Society staff stayed in the main hall so that carers could be assured that their person with dementia would be occupied and 'looked after'. Sometimes, small groups of people with dementia played cards amongst themselves. More than half of the carers attended the parallel support group.

The support group and craft hour finished in time for the closing hour's music performance. A local musician or group hired by the Alzheimer's Society often performed classics from the 1950s and 60s, with some encouraging dancing or leading sitting exercises. Echoing the Singing for the Brain service, described

below, music was a resolutely communal part of the Café. If the support group ran over its allotted time, the Café organiser would knock on the door to let the support group organiser know it was time to rejoin the Café.

The temporal and spatial organisation of Cafés, based around identities of carers or persons with dementia, was marked at these afternoons, and attendees followed along readily. The familiarity seemed to be a source of comfort, and underlines carers' and people with dementia's efforts to establish familiar temporal flow and spatial organisation in their own lives. Some cafés offered a shuttle service for people with dementia who had mobility issues. This was fiercely defended in the face of proposed budget cuts, pointing to the significance of mobility problems, the geographical range, and the strategies created to 'get out of the house', discussed in detail in Chapter 4.

### *Supper Clubs*

Supper Clubs are monthly social evenings where carers and people with dementia come together to have dinner and socialize. I regularly attended one of these supper clubs over the course of my fieldwork. Held at community centres in the more affluent boroughs, usually about thirty people, including carers (spouse, children, and sometimes both), people with dementia, staff and volunteers

attended. Carers and people with dementia arrived in pairs and small groups and Alzheimer's Society staff and volunteers greeted attendees upon arriving, collected a small fee for the event, and helped those with mobility issues to their seats. Tables were set decoratively, and a Sunday roast style dinner was catered in from a local pub. After everyone was served, volunteers joined carers, people with dementia, and staff at the tables and introduced themselves before joining in on chat about family or recent events. Care strategy-driven discussions typical of support groups was limited here. These evenings were relaxed, convivial, often involved music, and seemed to cater to the social needs of carers and people with dementia; many remarked, 'it's so nice to get out of the house and meet with friends'. People with dementia joined in and laughed along to dinner conversation, contentedly ate in silence, or snoozed in their chair. Their difficulties with eating, speaking, (or staying awake) were not often corrected in this setting. This echoes themes in the following chapters examining the ways in which carers and people with dementia seek social contact with people outside their relationship with one another, and the significance of social spaces in which dementia-related behaviours are understood and allowed.

### *Singing for the Brain (SftB)*

SftB sessions were held weekly in a large, open, brightly lit room within community buildings and had the most consistent membership attendance of all services. Between 20 and 25 attendees came to each meeting, along with 4 or 5 volunteers. Carers and people with dementia often came together, and this group saw the highest number of male carers coming with wives or mothers. Three people with dementia were routinely joined by both their spouse and at least one daughter (sons were never in attendance). Further, a few carers who had originally attended with a spouse continued to attend as official Alzheimer's Society volunteers after their spouse had passed away.

At SftB sessions, music was the central, binding activity; under the direction of a singing leader, everyone sang World War Two era songs. Here, music served as 'social lubricant' and created a 'temporally liminal' space, the focus of Chapter Six. Towards the end of fieldwork, a new singing leader took over and tried to introduce changes to the routine and song list, until the group's lack of enthusiasm steered the sessions back to the previous norm.

### *Positionality*

Considering the demographics of my fieldsite, it is important to note that I am a white woman. This allowed me to blend into my fieldsite to an extent although at

the time of my fieldwork I was in my 20s and therefore younger than most carers by at least 20 years, and closer to the age of a number of junior Alzheimer's Society staff members. Further, in some of my introductions to groups, I mentioned that my grandfather was my initial inspiration for researching dementia, because he had been diagnosed with Alzheimer's, and my family and I were very active in his care until his death. The combination of these factors seemed to give me a slight 'insider' quality for many of my informants. In passing, a few informants mentioned that I 'must get it' in terms of certain family dynamics and the difficulty of managing particular dementia symptoms. In witnessing how women carers often included male carers in group settings, I speculate that my presence in these groups was less disruptive than had I been of another gender, and that being a woman allowed me to be seen as 'in on' assumptions about the 'naturalness' of women as primary carers.

### *Limitations*

This thesis is primarily based on my time spent in support groups for people with dementia and support groups for carers run by the Alzheimer's Society. This allows me speak authoritatively on the dynamics, concerns and conversational contents of these groups, which so far is an under-researched site of collaboration



and lay expertise construction. Although many of the discussions in these groups were about people's everyday experiences and home lives, this focus has restricted my direct access and observation of people in their homes, and thus beyond what I was able to see and learn about in interviews. Further, those that attend Alzheimer's Society services are a select group, or the 'joiners' of the dementia world, as they were called in one 'dementia methodologies' workshop conversation of which I was a part. There are many, many people living with, and caring for, people with dementia who do not attend these groups and services and for whom the findings of this thesis would be inconsistent. My assumption is that many of these carers may be men, who might feel less comfortable attending support groups, or who might be less likely to reach out to formalised charities like the Alzheimer's Society and thus learn about these groups.

Additionally, in hindsight, I wish that my research plan had included alternative ways of capturing people's experiences of time and space. These might have included walking/driving interviews (a few of which I did, but only incidentally), as well as the co-production of visual diagrams *with* my informants, instead of diagrams I made based on interview and support group data after its collection (see Chapter 3). Such methods might have allowed me to ask in more detail about phenomenological experiences and to more fully integrate an emerging dementia

methodological ethos within the social sciences which seeks to collaborate with people living with dementia as co-researchers (Clark et al. 2018; Novak and Wilkinson 2018; Tanner 2012; Stevenson and Taylor 2017).

## **Chapter Summaries**

Chapter 1 explores the importance of chronological narrative in the lives of people in my fieldsite. I explain that the overall structure of this thesis, in which subsequent chapters centre on examinations of the past, the present, the future, and 'liminality', is not only a helpful device to my own end. I show that such a structure is in fact representative of people's efforts to make sense of, manage, and care for people with dementia across different periods in their lives. Carers and people with dementia learn to explain the cognitive and social challenges of dementia through a linear, chronological narrative style of discussion in support group settings. I also show, however, that such renderings do not easily allow for the spatial and temporal confusion that many people with dementia experience, in which conformity to normative perspectives of time becomes difficult. What also emerges is the importance of a timeline of dementia progression, on which carers 'plot' their own experiences and one another's relatives with dementia to determine 'how far along they are'. While this timeline of progression is of less

importance to my interlocutors with dementia, both carers and people with dementia 'map' one another within a social network of support to better understand what help people have, and need. Using information about progression and support systems, carers try to determine whether or not a person with dementia 'can still do things'. Similarly, when people with dementia talk about their support networks, they emphasise ways to maintain their independence. What becomes clear is the importance of autonomy in both groups. Resultant care strategies and solutions often centred on framings of linear time, by referring to the past as a source of identity, the present as where people with dementia should stay cognitively anchored, and the future as vague and uncertain. My thesis, modelled on a chronological rendering of time, takes seriously the normative temporal landscape to which my informants aspire. It also underlines care as a social support system, and as a set of practices aimed at maintaining people with dementia's independence and autonomy, even as their symptoms progressively worsen. In this, we see the tension between relationality and autonomy inform people's attempts to manage *over* time and *make sense of* time.

After establishing the importance of narrative and chronology in my interlocutors' lives, I then turn to what can be considered the starting place of narrative, where

a story begins. Chapter 2 is an exploration of how carers and people with dementia speak about the past in support groups and in interviews. I pay particular attention to how the past is used to bring clarity to the present, but also how carers and people with dementia engage with the past in ways similar and different. In both groups, who a person with dementia is and was, is not intrinsically linked with dementia, and a person with dementia's identity and personality is established retrospectively by drawing on biography. Carers look to the past to figure out the 'beginning of the dementia' in their relative. By reassessing their relative's past behaviour to recall when they started acting 'differently', carers re-label past odd behaviour as 'dementia' and not as representative of 'his old self' or who a person with dementia 'really is'. In this, a distinct separation between people with dementia and dementia itself is created, that works against ideas that 'who' a person with dementia is has been destroyed: instead, they are 'lost'. Amongst my interlocutors with dementia, engagement with the past is much less dementia-focused. Instead, it is the biographical anecdotes revolving around past careers or family life that highlight accomplishments and experiences shared that take precedence, and they ground their identity in such anecdotes. Dementia is cast as a nuisance and peripheral in their lives, not intrinsic to their self-identity. Modes of chronological narration are used in both groups to establish people with dementia and carers as socially

embedded individuals whose identity can survive the rupture of dementia in the present, through a remembrance and iteration of the past.

Moving on from the past, my examination turns to the present and explores how the people with whom I worked managed some of the most pressing issues of their everyday lives. Chapter 3 focuses on challenges wrought by temporal and spatial disorientation, and a person with dementia's difficulty making sense of and keeping track of time, and remembering and navigating spaces familiar and new. In response to these disorientations, strategies were crafted that centred on helping a person with dementia to understand time – both as an abstract construct, and also as a marker of social patterns. Ways were crafted to curtail a symptom called 'wandering' in which people with dementia leave the house at night and risk becoming lost, and to allow for people with dementia and carers to leave the house to pursue 'my own things'. These disorientations highlight the importance my interlocutors place on household routines as well as 'getting out of the house' and how the progression of dementia often meant that carers and people with dementia became tethered to one another by a mounting dependency. I underline their need for a balance to be struck between the two spaces – but also in the relationship between a carer and the person with dementia. Chapter 3 also explores the ways in which time and space overlap in

my informants' disorientations and strategies. I show that remaining tethered to their relational networks as well as their identity as independent, autonomous individuals requires doing the 'right' thing at the 'right' time and in the 'right' place. Making sense of spatial and temporal aspects of reality become implicated in notions of whether a person with dementia is 'still there' and 'able to manage on their own'. The significances of the home as a site of care, kinship, and relatedness, and the 'outside' as associated with independence and autonomy also emerge and inform carers' ethical concerns about confining their relatives' 'freedom' in an effort to keep them safe. I also describe how these spaces' gendered associations shape what is deemed an appropriate adjustment to people with dementia's activities inside and outside the home. This chapter unpicks the ways in which my interlocutors' strategies in response to temporal and spatial disorientation are, at their core, aimed at two things: negotiating the interdependency between carers and people with dementia, and finding a way to balance people's ability to remain independent, while also staying included in the social flow of family life.

While the strategies to manage the challenges of the 'present' were specific and much discussed in support groups, the approach to the future differed. In Chapter 4, I address how people thought about and planned for 'the future', or, rather, did

not. Standing in contrast to their pre-dementia relationships with the future, dementia creates a rupture in the engagement with certain temporalities. In support group settings and interviews, 'the future' is uneasily framed as 'not having happened yet' and not able to be planned for or imagined in concrete ways. The uncertainty of dementia progression creates an almost impossible task in which my interlocutors sought to avoid direct discussion of the future whilst also ensuring that they 'planned for it' to safeguard family finances and harmony. They navigated the 'hassle' and confusion of legal documents such as Medical Directives (MDs) and Powers of Attorney (PoA), and bureaucratic paperwork to arrange for care support and services in anticipation of future needs. Legal and bureaucratic documents with standardised decisions were mostly completed based on 'how everyone else does it', rather than on personalised plans for the scenarios that could arise. Interestingly, 'the future' was only given form during discussions about these documents, and in contemplation of the experiences of other group participants who were 'farther along [in the progression of dementia]' who represented 'what might happen', underlining the significance of a timeline of dementia progression. MDs and PoAs were framed as a way to protect a person with dementia's current wishes and autonomy against the progression of their illness or their family's ignorance of 'what they would have wanted'. As such, these documents were seen to temporally suspend a person with dementia's decision-

making ability past the point of legal and cognitive capacity. Novel dynamics of care and relationality emerge, and centre on a seeming paradox: acknowledging a person with dementia's growing dependence and care needs, while also seeking ways to maintain their autonomy and control. My informants' pursuit of these difficult and time-consuming paperwork processes also required navigating tricky relationships within their family, and often caused many carers to grow frustrated with the state during long waits for services or assessments. I link people's willingness to navigate the 'never-ending hassle' of these paperwork processes to their underlying desire to keep their relative with dementia 'still there' by 'doing what he would have wanted'.

The final chapter of my thesis, Chapter 5, stands in apparent opposition to previous chapters' explorations of how my interlocutors' sought to maintain a narrative linearity in their lives. Taking Singing for the Brain (SftB) sessions as my focal point, I show how these sessions' communal activity of singing is rooted in participation and reminiscence. I argue that the set-up of these sessions constructs a liminal space in which people with dementia and carers can connect with one another in tender and affectionate ways, not commonly seen in other official settings in which I spent time during my fieldwork. Communal singing of a repertoire of World War Two era songs drew on people's recognition of words



and melodies from their youth, but did not test the person with dementia's cognitive ability to remember or reiterate memories accurately, creating an activity founded on reminiscence, as opposed to chronological recall. A wider range of behaviour is tolerated and encouraged in these sessions, which minimize dementia as a defining label and recognise people's unique preferences and personalities. I suggest that SftB sessions create a sense of intimacy and camaraderie that establish attendees as social equals. What became tantamount to sociality in these spaces was recognition of participants' willingness to *partake* in singing and conviviality, and their desire to connect with others. In this, despite being 'temporally untethered', a person with dementia could be seen as a self-possessed, independent person with whom their loved one could still connect, and meet on tender and affectionate terms, beyond time.



## CHAPTER 1: Mapped and plotted: learning to construct narratives in the midst of dementia

Weather reports promised that the season was turning toward spring, but rain formed a cold curtain over the door of the Carers' Centre. I waited, poised with a tea kettle in one hand, a jar of instant coffee in the other, and an over-friendly 'good evening' on my lips. Julia, the Alzheimer's Society facilitator of this support group also said hello to people as they arrived while I prepared drinks – two teas with milk, a black coffee with sugar, two coffees with milk, one coffee with both. I silently repeated members' names and their drink preferences under my breath, committing both to memory. Over time, my memory and making of a person's drink to their preference without needing to ask would come to be a defining task of my role as a volunteer. It became a way by which others recognised me, and I them. With a quick nod to Julia, I sat in the empty chair just outside the small circle

of people. She then introduced herself as a 'facilitator – I'll help run the group, but we'll use this time to talk about your own experiences'. She also introduced me as 'a student researching dementia I asked you about last week' and I spent a minute explaining that I was part of the group as a volunteer, but was asking permission from the group to take anonymised notes on the evening's meeting as part of my PhD research. After a prompting from Julia, the group members all said they were happy for me to be there, with one woman mentioning, 'You'll certainly learn a lot about dementia from us!'

The group then got underway with Julia suggesting that everyone introduce themselves and give a 'recap' of their past month. The women, all of whom had been regulars of this group, quickly followed Julia's directions and spoke for about five minutes each. Attention then turned to the new member of the group, and the last in line to introduce himself. Richard's face was drawn, and framed by thick brown hair streaked with grey, spreading outward from his temples. He sat forward, with his elbows balanced on his knees, gently pulling up his trousers to show subtly mismatched socks – one a faded slate, the other a dark blue. His hands hung limply from his wrists and exhaustion ran through every line of his body. Richard, though one of the rare men to attend a carer support group, was the picture of a new carer joining a group. Julia leaned in, mirroring Richard's

posture and spoke quietly, saying, 'Richard, why don't you introduce yourself to the group?'

At this prompt, Richard said, 'Evening everyone, my name is Richard. I care for my wife, Emily – she has vascular dementia and...and she's home most of the time. It's been...difficult.' Richard's voice was a muted rasp. The small room was quiet, and the soft sounds of its six occupants made only a slight dent in the silence that punctuated Richard's admission. The five women sitting around Richard nodded. One gently pushed a plate of biscuits toward him while another subtly shifted her knees in his direction.

Julia interrupted the silence that followed. 'It took a bit of coaxing to convince Richard to come...' she explained, and lifting his head, Richard answered, 'Yes, I was a bit reluctant, I wasn't sure anyone else would understand...'

Other carers in the group nod, and Viola, who cares for her husband, said, 'Yes, you can feel so isolated, but this group – it makes you realise you're not the only one.'

Shonda, who cared for her father, added, 'Yes, we talk about what we're going

through and the ones that have been around for ages [smiling to one of the older, resident carers] are helpful to the rest of us – they've been through it all...'

Julia explained, 'It's important to get support when you're caring for someone with dementia – and this group is full of people knowledgeable about caring for a person with dementia! They know what's ahead of you, and also what you've been through already.'

Gillian, a soft-spoken woman who rarely contributed to group discussions, explained, looking at Richard, 'I was so exhausted when I first came...after my first group, I came away feeling so much more sorted – I knew who to call about services, what paperwork needed doing. I didn't really know how things with Theo [Gillian's husband with dementia] would go, or what we'd need, but in the group, they help you...sort it.'

While Gillian spoke, Richard returned her gaze and subsequently began to meet the eyes of the other members of the group. The sombre tension of the group was broken by this conversation, and Richard began to look visibly relieved. Everyone spoke a bit louder, and after the carers described their own experiences, the discussion turned to focus on Richard's circumstances. Others sitting around

the table took turns asking him questions, with an almost rhythmic coordination, as though they were sharing a script.

Shonda began with direct, short questions: 'What sorts of things are you having to do for her – at home? How long have you been helping her?'

Richard's answer was slower, and meandering. 'I'm not sure what to do with her really, her memory's gone quite a bit at this point, and she needs so much reminding...asking when we're going to the shops when we've already been...she follows me around, and Em [his wife] can't cook anymore so I've had to do all that. I'm not a cook exactly...and she's started needing help in the toilet, I think, she doesn't always smell...clean...but I'm not sure I should be in there with her.'

Rhonda listened thoughtfully, and then followed with, 'So, her memory problems – those became much worse recently? When would you say they started?'

Richard's answer was short, and noncommittal, a verbal shrug. Rhonda pressed her lips into a slight line, before she said, 'Alright, then you need to see what she remembers and what she doesn't – watch her or ask her to do things, like getting dressed by herself, but don't leave her alone with anything dangerous until you

know more.'

Viola joined in as well, and said, 'You said she had vascular [dementia]-- it's like they go in steps down with that type; suddenly you find that they'll lose things quite quickly – that's what happened with Gareth...was fine going out on his own, then one week to the next, he started getting lost.'

Preeti nodded, adding, 'Yes, that's true – it's different in my aunt's Alzheimer's but still, it's good to keep track of these things because...then you find one day that you wake up and don't know how you got to where you are now! Have you been speaking to her GP regularly about how she's doing?'

Another carer peppered Richard with, 'And what about family? Is your daughter a help?'

'Right,' Julia chimed in, 'Have you spoken to your family about your wife?'

Richard answered all these questions, hesitating at some as though he had just considered their portents for the first time, that evening. He wrote down notes as the other carers gave him advice, and his pad was etched with the names of staff



members who 'were good with paperwork', the telephone number of a professional carer agency, and information about CrISP, the informational seminar for carers run by the Alzheimer's Society. Julia passed him a leaflet about dementia with the word 'progression' in the title. When the group moved on and discussed other topics, I watched Richard listen to the discussion closely and his posture subtly altered. When the group finished, his shoulders were slightly more squared and his eyebrows less furrowed.

In this opening scene, we see Richard introducing himself to the group, but also see the group introducing themselves, and importantly, the conventions of the group, to Richard. After Richard's initial reticent account, the other group members took the lead. They marked out, through their persistent questioning, which aspects of his daily life, wife's diagnosis, and relationship with his wife and family were significant to the purposes of the support group. They also subtly signalled how these were constitutive of his identity within the space. These pieces of information, and Richard himself, were then made sense of and arranged conscientiously on a dementia progression timeline and also within a body of collective medicalised knowledge. I take these themes as points for further examination in this chapter.

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This chapter explores the distinct and unique spaces of support groups for carers and support groups for people with dementia, and the narrative framings of conversations that happen within these spaces. The spaces were decidedly different from the spaces that my interlocutors inhabited away elsewhere, such as their homes, doctor's offices, community centres, and the more social services, such as Singing for the Brain, Caring Cafes, and Supper Clubs. Support groups were where the tautest conversations about the management and progression of dementia took place. People said that they could 'tell the truth' among peers. The meetings were spatially and temporally-bound spaces filled with knowing glances and nods, and incisive quips as people took advantage of a chance to vent and recoup among peers. Conversations were seen to be 'about what it's really like' and, in many ways, a distillation of the concerns and conceptualisations about dementia voiced more casually, or obliquely, in other social settings. Indeed, many people referenced support groups in our interviews, and spoke about how meetings had affected their experiences and perceptions of dementia. Group meetings are a crucial source of much of the material explored in the chapters to follow.

The opening ethnographic material above is representative of a typical support group for carers and illustrates my discussion about carers in the first half of this chapter. In Part Two of this chapter I provide further ethnographic material describing support groups for people living with dementia. I use this to show how similarities emerge in how both people with dementia and carers learn, and strive to narratively frame their experiences in these groups, albeit in different ways and to different ends.

Within each chapter part, I tease out how carers and people with dementia are introduced to, and introduce themselves within, their distinct groups and settings. The particular narrative structures that pattern each kind of groups' discussions is illustrated, showing that carers mainly craft disease trajectories, and people with dementia biographically narrate their lives. My discussion then shifts to how support group members work together to understand what dementia *is*. I show that they do this by operationalising – or not – medicalised, and other, framings of the disease to inform these timelines.

Currently, there is a breadth of scholarship and policy attention on the needs of carers of people with dementia and support services but there has been scant research on the specific spaces of support groups for carers and support groups

for people with dementia. Work on the subjective experience of dementia (Cheston and Bender 1999; Harris and Sterin 1999; Kitwood and Bredin 1992; Sabat and Harre 1992) shows that people with dementia are not passive subjects, and some emphasis on the positive value of psychosocial treatments such as 'cognitive stimulation in a group setting' emerges (Droes et al. 2011). Furthermore, much of the research on carers and people with dementia, as well as support groups, has a medical focus. Reports and evaluations are most concerned with services' ability to reduce negative markers of wellbeing such as depression, anxiety, loneliness, and carer burden. The research questions are posed against a backdrop of the perceived slow catastrophe of dementia, in which a person with dementia's working memory, thinking and emotive capacities, and, eventually, their self, identity and personhood disappears (Klein et al. 2003; Cohen and Eisdorfer 1986; Fontana & Smith 1989; Orona 1990; Ronch 1996).

In contrast, I examine support group services, separately and side-by-side, as social worlds in which people come together to craft new meanings of their experiences amidst the encroaching confusion of dementia. I work from the view that carers and people with dementia are not easily separated from one another. While their experiences with dementia diverge, they, as people on either side of a particular kind of relationship, are nonetheless in conversation with one another.

My focus is not on independently evaluated scores of psychological wellbeing, but instead on how these groups are used to 'figure out how to manage' on their own terms what which aspects of the disease and their experience they want, or to need, to discuss. My examination is thus anthropological, and less policy-orientated. I bring a concern for the habits and customs of dementia care and management, and conceptualisations of the disease among my interlocutors who attend Alzheimer's Society services in London.

A discussion of dementia care and management, I argue, necessitates an understanding of how people engage with time and temporality. Some attention has been paid as to how carers of someone with dementia in western settings organise their experiences into normative narrative structures with temporalities of past, present, and future, or sequence events into categories of before and after (Becker 1997; Caldas and Berterö 2012; Orono 1990). The importance of the narrativisation of the illness experience to patients and carers alike has also been well documented (Kleinman 1989; Strauss et al., 1985). Less common is work that situates this examination within formalised spaces such as support groups, how people with dementia self-describe their own experiences and lives (Harris and Sterin 1999; McGowin 1993), and whether these descriptions take on normative narrative structures similar to those of carers.

I thus build on work examining links between dementia and temporality by looking particularly at how the formalised activities of support groups reinforced and instigated a pursuit of normative narrativity. I draw on Pols' work on telecare devices, in which she explains that, 'the devices and their users solve particular problems by cooperating with each other, but in enacting these solutions together, *they also shape what these problems are*' (Mol, Moser, and Pols 2010: 173, original emphasis). While Pols' research focusses on the device of a telecare system as a tool of self-care, I position support groups and their emphasis on narrative as tools of care.

In such a configuration, carers' and people with dementia's cooperation with one another to narratively plot and socially map one another, 'shapes' dementia's problem as a confusion caused by non-narrativity or social isolation. Indeed, due to specific stipulations issued by funding bodies for Alzheimer' Society support groups, staff members had to emphasise their purpose as 'information and support,' instead of their prior emphasis on respite. One staff member explained, 'support groups can't just be about having a nice time, apparently, they want everyone to go home having learned something.' Considering this, this chapter emphasises the importance of chronological narrativity and suggests its

positioning as a 'solution' for my interlocutors.

It is important to draw attention to such a linear and chronological ordering of time, despite the fact that it may seem given or normative (Strawson 2008). The experience of living with a diagnosis of dementia, or caring for someone with the condition, throws the divergence between such conceptualisations of time and its lived experience into sharp relief (see especially Chapters 4 and 5). People with dementia's challenges with temporal disorientation disrupt an ordered, sequential, chronological experience of life, marking them as possible 'episodic' people, who live and experience their lives non-narratively. Non-normativity poses threats to personhood, and in response, many carers and people with dementia appear hold tighter to narratives about their experience, which present their lives as chronological timelines. As such, this chapter also situates itself within social science debates about the usefulness and pervasiveness of narrative within health research (Christman 2010; Hyvärinen 2012; Strawson 2008; Thomas 2010). My research shows that my informants' narrativity, normative or not, is linked with self-making. Establishing 'who you are' as a person was often the goal of telling stories about their past, present and future lives for carers and person with dementia. In drawing on work concerning the iterative and narrative process of identity-making (Day 2008; Kaufman 1986; Lambek 1996), I show that the

narratives shared in support groups serve to construct the identities of carers and people with dementia differently. Predominantly, carers are established *as* carers, and people with dementia as people whose identities are not solely defined by their diagnosis or as a 'cared-for' person.

However, in both groups, these constructions are also challenged by an underlying acknowledgement that help is needed; one cannot be a carer only without burning out, and it is impossible to manage dementia alone. I also foreground how people with dementia and carers are bound together by this dependent caring relationship. In doing so, I suggest that independence and 'still being there' – either on the part of the person with dementia or their carer – is a constant, underlying concern. It motivates why carers seek out these groups, and what they want to find out about how to *be* a carer and 'manage'.

## **Part One: Support groups for carers**

### *Constructing Timelines of Care*

When new carers join a support group, they are given space to introduce themselves to the group at their own pace. In the account at the start of this chapter, we see that in Richard's case, this came slowly. He was shy, tentative and



the group responded in kind, listening quietly to his description of home life as 'difficult.' But once his own short description was done, he was peppered with short, direct questions and anecdotes. Other group members wanted to know when 'things' began, when particular symptoms had emerged or changed, and when or if he had had conversations with other family members about his wife. If a carer seemed particularly overwhelmed, they are often asked a range of follow-up questions, which delved more deeply into the particulars of what they had told the group. Carers were asked about medically and care-giving significant events which 'happened before' current experiences, and whether they had 'made preparations yet' for the future or what they understood 'might be coming' in terms of dementia symptoms. Anecdotes and information shared were ordered chronologically by the structure of these conversations, and particularly the introductions made in these support groups. By positioning the moment being experienced in the support group between a past having taken place beforehand, and sets of future possibilities with which carers may have to contend, the 'present' with its challenges that need to be managed *now*, emerges. Here, the pertinent point is that temporalities are established as separate from one another, each with its own concerns and challenges.

After the group's onslaught of questions for Richard, most carers greeted the

group with a swift recounting of their recent experiences, as though their words were gas escaping a pressurised balloon. Many explained that they had various concerns, but relayed those that felt most pressing, frustrating, or for which they sought advice. In almost all cases, carers' recountings were made after an invitation from an Alzheimer's Society facilitator to introduce themselves or 'tell the group what's happened since the last meeting'. While facilitators did influence what was discussed, and how, in another group that I regularly attended which organised collaboratively by a group of carers and by the Alzheimer's Society, I found the same format of introductions. Carers always gave their name, told the group who they cared for, and their relationship to their person with dementia. In some groups, where the group membership was the most consistent and long-standing, a carer's turn to speak might be prompted by another referencing known details in another's narratives of caregiving. Questions similar to: 'How are things with Gerry, Victoria? Any luck with the shuttle to the Day Centre?' were common ways such references were made. Support group meetings were thus often structured with a focus on capturing the latest instalments in the *story* of people's lives.

Follow-up questions become a method by which the group at large worked to understand a carer's position 'along' the 'dementia journey' or caregiving

trajectory. This is reminiscent of histories taken in clinical spaces, in which a patient's symptoms are ordered in sequences of 'before' or 'after' one another to aid in the diagnosis of a medical condition, to gauge the advancement of the illness, and to offer a prognosis (Frank 1995; Kleinman 1988; Mishler 1984). The key difference here is that while carers do take an interest in the clinical and medical presentation of dementia itself, discussed further below, carer groups also work to ascertain how far 'advanced' the caregiving of a carer is. This is not a suggestion that caregiving is an illness (although the concept of carer burden and its significant effect on caregiver wellbeing is well-established) or that carers see their role in this way. Instead, I wish to underscore how seriously carers, particularly long-standing carers, regard the undertaking of caregiving. 'So many crazy things happen when you're looking after someone who has Alzheimer's – this [being a carer] isn't a damn joke!' – one carer lamented.

While caregiving is not classified as an illness, carers' engagement with illness narratives lend insight into the ways in which carers take account of, and question one another about, their daily routines and tasks. They plot each other on recognisable timelines in ways similar to those with chronic diseases. While they do not regard their own experience as a medicalised one, they are nonetheless aware of the *prognoses* of long-term caring, that 'caring takes its toll'. As one

carer whose family had sent her on a month-long respite break explained '...letting things go on, not taking any breaks or telling anyone, and then before you know it, you can't really go on, can you? You can't get out of bed even though you know he [her husband with dementia] needs you, but I was so exhausted, tired...could't stand answering the same questions again...just no use anymore.' Alzheimer's Society staff try to educate carers in support groups and CrISP (Carer Information and Support Programme) about concepts such as 'carer burden' or 'burnout', and often advertised these services during discussions about the dangers of prolonged caregiving.

### *Using Timelines of Care to Plot Dementia, and Vice Versa*

The narrative practice in support groups that works to plot a carer along a caregiving trajectory is also used to work out how advanced was the dementia of their own, and other people's relatives. Projected timelines of 'how being a carer will go' is often inexorably linked to their family member's dementia progress. For carers, they often form a loop, in that a carer's examination of their carework and its progression is used to inform understandings of how extensively their person with dementia's illness has progressed, and vice versa. A spike in a carer's accumulation of tasks, worries, responsibilities, and often, the need to stay home

(discussed further in Chapter 3) are used as clues to determine whether a person with dementia has 'moved into a new phase' or 'gotten worse.'

To illustrate, I describe what Tara, a middle-aged woman who cares for her elderly husband with Alzheimer's, shared during an evening carer's support group in the winter of 2015. She explained, 'He's really just having trouble remembering what he's got on, just needs me to make sure he checks the diary most of the time now'. Other carers responded, describing her as 'just starting out' and that her husband's dementia was 'earlier' than for others in the group. A comparison was drawn with Ruth, whose experiences were 'farther along' because her husband's '...been having a difficult time. He keeps thinking the children still live at home, asking me where they've gone- shouting to me when he can't find them, of course.' In this, we see that labels such as 'starting out' and 'farther along' chronologically sequence caregiving experiences and responsibilities and tie them to specific temporalities, but also that certain types of carework inform the sequencing and positioning of their person with dementia on their own separate timeline.

Likewise, specific behavioural symptoms of dementia are used to inform carer groups' discussions of what being a carer entails, or what the carer 'is in for'.

Medicalised behavioural symptoms and carers' interpretations of dementia progression will be discussed in their own right in the next section, but here I point out that in carer groups, participants listen intently to how other carers describe their person with dementia. What kinds of new caregiving tasks and responsibilities someone 'should be doing,' or 'might be coming' are often tied to dementia progression timelines. This link also surfaces in the way in which carers contemplate the advent of their caregiving (discussed further in the next chapter), and the intricacies of what future responsibilities will include (discussed further in Chapters 3 and 4). In the cases of new carers who come to the group overwhelmed because they were 'not sure what to do', links were made between dementia symptoms and caregiving tasks most obviously. Returning to Richard's case from the opening vignette, we see that carers used collective knowledge to offer him advice. This collective knowledge was created over the course of many meetings' conversations about their own empirical understandings about which symptoms go hand in hand with which kinds of carework. The carers advising Richard detailed which organisations or staff members he should call, the importance of communicating with family, and how to 'check' on whether his wife could still dress herself unaided. In effect, they mapped out an appropriate script to follow as well as a defined role to play. The collective aim was to 'get things sorted' and have him 'start off on the right foot' before finding himself 'in too deep'. Thus,

support groups are spaces in which people created and shared working knowledge of dementia in order to try to keep one another on the 'right track' so that the unfolding progression of their experiences 'don't go pear-shaped.'

*If you talk like a carer, walk like a carer, you're a carer*

In the material presented so far, we can see ways in which a carer's identity becomes inexorably linked to their person with dementia. Notably, carer support group members learned that they were *carers*, distinguished as a role beyond that of spouse or daughter or other relative in these meetings. New members of a carers' group were often told 'You're a carer now' during their first visit; indeed even the name 'Carer Support Group' encourages a strong identification with the term. Group members' willingly and universally used this term to describe themselves in the abstract, alongside providing specific detail of their kin or social relationship to the person they supported. In learning about what providing care entailed, people who attended these groups were taught that they occupied the role of carer, mirroring findings from research in Canadian settings in which caregivers who were brought together in family support groups meetings were able to self-define themselves as carers rather than simply as having extended their caring role.(O'Connor 2007). The uptake of this term to describe their role is

no small feat. Research on communication strategies to reach people taking on significant caretaking responsibilities for a family member or friend has suggested that lack of identification with the term 'carer' is a major obstacle to reaching carers in communities, and a reason that so many carers are considered 'hidden' from local authorities (Carduff et al. 2014; Pickard et al. 2016). Thus helping carers to identify as such, in sensitive ways that do not cause offence, may be the first step in effective outreach and in convincing carers that they are in fact eligible for carer support services.

Tara's and Richard's narratives above show that their identities as 'carers' emerged from joining the support group, and from the group's efforts to take stock of and chronologically order their experiences and activities centred on the support of their spouses with dementia. Interestingly, 'being a carer' was often not seen as a static role, but as one that mirrored the progression of dementia. For example, another carer told Tara that she had begun 'by giving him a bit of help remembering his appointments too'. Now she phones her daughter or the GP surgery to check that her husband has arrived, but has been told by others that she might soon need to consider driving or accompanying him to all his appointments: 'You become more and more of a carer, as they need you, I suppose.' The identities of carers are thus constructed along a 'continuum of care'



(Gillies 2012: 673) in which many of their daily activities come to be seen as 'care work'.

In encouraging identification with the term carer and the care work which this role entails, support group discussions often simultaneously positioned a person with dementia as a care recipient dependant on others' support. Indeed, in this context, would a carer exist as a carer without a person identified as a recipient of their care? This mirrors what others have referred to as the 'the patienting process' in which people with dementia are socially set apart from other family members (Adams 2001), referred to as 'malignant positioning' in research that calls for interactions with people with dementia to support social inclusion as a way to maintain personhood (Kitwood 1997). However, as other research in western contexts has shown, this identification of one's spouse, parent or friend as a 'care recipient' was not straightforward and 'family members often see the work they are doing as simply an extension of their relational role' (O'Connor 2007:167). The uneasiness about naming a family member as a care recipient also underlies the persistent challenges in identifying carers, cited above. The Canadian caregivers In O'Connor's study, attenders of carer support groups, 'continued to rely upon a more conventional kinship story-line to construct their actions and understandings, [because it] mediates the risks of constructing the family member

who requires help as an 'other' (O'Connor 2007: 173). This applies in my fieldsite too: carers always referred to the person they cared for by their names and kin relation, alongside indications of dementia and care needs. For example, common opening comments were 'My husband's Bob, he's got Vascular', 'I take care of my wife', 'I help look after Dad, he was diagnosed with Alzheimer's last year and I think he's getting a bit too much for his wife, my step-mother to handle on her own now.' While O'Connor's work suggested that those family members she worked with resisted naming a person with dementia as a care recipient, in the settings of my research, carers' uptake of the term carer coincided with a careful balance between an identification of a person with dementia as in need of care as well as a person occupying an important familial position.

While identity loss in people with dementia is a common trope in research on the subject (Beard 2004; Robertson 2014; Perkinson & Solimeo 2014), less common is discussion of the loss of identity on the part of carers. I suggest that identity loss is a common sacrifice which carers make in the line of care. My interlocutors grieved for their identity as kin to their person with dementia, and as people with careers and occupations outside of caring, and as people who could 'do what I wanted when I want to do it!' Hans, an elderly carer who lived with and cared for his wife, explained in a group meeting that he missed being

'...just her husband – but you know what she told me last night? She told me she was thirsty and then says, 'Bring me a glass of water.' And I say to her, darling, that's not very nice – can't you say please to me? And she tells me, 'But you're here to take care of me! I don't have to say please!'" He shook head, saying, 'That was never how we spoke to one another when we were just man and wife.'

Han's story illustrates a darker side of care, in which providing care, and the expectations of care, are experienced as a threat to kinship. I suggest that while care has been positioned as a practice generative of kinship, this generative quality is not necessarily given. Needing to provide care beyond that which is expected of the role of husband, for example, or without the balance of reciprocity, as implied by Hans' wife's expectation and lack of gratitude, endangers Hans' feeling of connection to his wife *as a husband*. As such, care in kinship contexts is only generative of relatedness when it is kept within careful boundaries.

Other carers spoke with similar pain at the erosion of self they felt as their caring duties superseded time formerly spent on hobbies or socialising with others. I was told that 'after a while it can seem this [being a carer] is the only thing you are, really'. Because of this submersion into the identity of 'carer,' spaces such as the

support groups, Caring Cafes, and other Alzheimer's Society services were a 'godsend' because 'here people understand, and you can admit, you know, sometimes I hate this and that you miss your old self' and 'so many of the other women in the group have found ways to still have a life, so it's helpful because you get advice on taking care of someone with dementia, but you're also told that you can't be a carer *all the time*'.

To find this balance between being a carer and their 'old self', group members are encouraged to consider asking for 'outside help' or support from their wider family and social circles. The significance of wider support networks in the management of dementia and caretaking duties is further explored in Chapters 2 and 3. Here, it is important to note that as a carer's identity was inexorably linked to their person with dementia's dependence on them, their sense of self was markedly staked out in conceptualisations of independence from this carer/cared-for relationship. The importance of space, particularly through the lens of *distance away from others*, is discussed further in Chapter 4. Carers' ability to make their own decisions, and to be elsewhere, constructs and expresses a sense of autonomy and individuality in their lives, and had to be carefully planned for with the help of others. Carers' identity and personhood both become implicated in the progression of dementia and highlight dementia's dimensions as a *social*

*illness:* the social relationships and lives of those a person with dementia is connected to become affected.

Although theorised as a social illness, dementia is also a medicalised condition. I now examine how carers engage with medicalised knowledge, use it to construct a dementia progression timeline, plot themselves and those whom they care for along its course, and distinguish their family member with dementia from others living with the condition.

#### *Dementia types as a way to order experiences and care*

Beyond categorisation of people's experiences into 'past', 'present' and 'future', group members also categorise their caring experiences according to labels of dementia type, the most notable being 'Alzheimer's', 'vascular [dementia]', 'mixed [dementia]' and more rarely, 'Lewy bodies [dementia]' or 'Frontotemporal lobe dementia'. Dementia type often featured in conversations in which members compared and contrasted their different experiences, and was part of the collectivised knowledge built up over time in support group discussions. 'Outside knowledge' about medicalised depictions of dementia types found in pamphlets and flyers at Alzheimer's Society services, carer centres and GP offices, in books

on dementia or caring, and in conversations with GPs, friends, family and Alzheimer's Society staff also featured in group conversations. My informants' first encounter with 'dementia type' was most often in clinical contexts during the diagnosis process (explored in greater detail in Chapter 2). Many carers explained that they thought that arriving 'at an actual diagnosis [type]' would promise some specificity and certainty, or substantial insight from the GP about 'what to expect going forward.' However, as other research has found, diagnostic categories belie the ambiguity of biomedical understandings of prognosis and causation, dementia types, and senility (Lock 2013). I argue that instead of biomedical conclusiveness, carers' groups are industrious and collaborative spaces in which dementia types are used as a jumping-off point to generate working knowledge about dementia prognosis and diagnostic categories. I suggest that these understandings about the 'timeline' of dementia are also used to order their own caregiving experiences.

The custom of attending to dementia type in group conversations was most notable if a carer did not volunteer which kind of dementia their person with dementia had been diagnosed with in their introduction to the group. In almost every one of these instances, carers would ask 'what kind of dementia did the GP say he had?' as can be seen in Richard's case at the start of this chapter. If carers

are unsure, the group makes efforts to find out the necessary knowledge to make a best guess. 'Problematic dementia behaviours' a person might be exhibiting are asked about, including such things as pacing around the house, marked agitation, mood swings, 'nervous ticks' like rolling up papers or hoarding items in pockets. Hygiene habits and concerns are also discussed, and, less often than might be expected, specific cognitive changes related to memory. Carers take care to ask about these changes, but also ascertain the rapidity of their onset. In a number of group meetings, carers also asked about brain scans and memory tests that a person with dementia might have undergone.

After gathering specific disease-related information, the groups compare a carer's description with what other carers in the group had experienced as part of 'the type of dementia' their family member with dementia had been diagnosed with. Parallels between carers' experiences who identified with particular types were drawn, and the support group as a whole strove to make an 'educated guess' about what kind of dementia a new carer's person with dementia might have. Returning to the description of Richard's case, the impetus for this group effort to ascertain diagnostic category is illustrated by Viola and Preeti's almost immediate acknowledgement of Richard's mentioning of his wife's vascular dementia. Other examples abound, and here I describe a few.

During an evening support group meeting half way through my fieldwork, Roxy, a carer who had recently joined the group explained that her husband

‘...says the most incredible things – the other day we were in the shop and he goes to the woman in front of us ‘you must be having triplets, you’re gigantic!’ and she wasn’t pregnant! I felt awful, I apologised for him but [puts her face in her hands] ...and if we’re out and he eats something he doesn’t like, he just makes a face – says for anyone to hear, ‘God, that’s awful!’

This was immediately met with a knowing nod from the other carer sitting across from Roxy. Tanya, who had been coming to the group for about a year, offered, ‘That sounds like Lewy-Bodies, dear, another woman’s husband who used to come to the group had it – in that kind dementia, it’s affecting the bit of his brain that knows what’s rude or not.’

At a different meeting, Thomas explained his wife’s mixed dementia by delineating cognitive and behavioural issues between the types commonly associate with ‘mixed.’ He linked ‘her problem with memory’ to Alzheimer’s, and linked outbursts of aggressive behaviour, ‘like when I try to tell her something and she calls me a liar!’ to vascular dementia.

Pamphlets available at carers’ centres and Alzheimer’s Society services detailed



long lists of cognitive and behavioural symptoms associated with different dementia types that revolved around memory, communication, planning difficulties, and impaired judgment and inappropriate behaviour. Sometimes physical symptoms were also sometimes included, but linked to 'later-stage' dementias and mimicked the care needs (such as feeding or toileting needs) of many chronic, late-stage illnesses. In scouring an individual carer's experience for 'clues' that might reveal type, carer groups look for specific constellations or the heightened presence of particular symptoms that match information found in sources such as these pamphlets. A similar search for 'clues' also occurred in carers' examinations of the past (discussed in Chapter 2), in which they try to ascertain when the dementia 'actually started', underlining that the temporal sequences of symptoms is also pertinent information.

Vascular and Alzheimer's, which had quite similar signifier symptoms, were often more precisely differentiated by the pace of their progression. Vascular was described as a rapid onset of challenges to memory and abstract planning with plateaus in cognitive decline, whereas Alzheimer's, as one carer put it, 'happens quite slowly; I wondered for a long time if I was imagining that he was mixing things up'. Additionally, the sequence of symptoms was also cited by carers as important in trying to determine the type of dementia. For example, a woman

who had recently taken on significant caring responsibilities for her mother explained that her mother's Alzheimer's fitted 'what [she had] learned in CrISP' in that she began to notice that her mother first began

'...forgetting things, then she had trouble with communication a while before her mood swings started. We'll ask, 'Do you know what day it is?' and she'll be almost sneaky and say 'Oh well, why don't you tell me?' and then get angry with me and quite moody and say things like 'Oh, so you're not going to tell me then!'"

During an interview, a carer told me that her father was

'classic Alzheimer's...it was really only his memory that we noticed early on, and that's been getting worse, bit by bit. He doesn't have any aphasia like Carol's [a carer in the group she attends whose husband has vascular], he'll talk to anyone, but you see sometimes that he has a hard time understanding what you're saying. I suppose that's just what's coming next.'

In these examples we see that dementia type is important to group discussions. They became carefully constructed tools that knit together medicalised knowledge of dementia type prognoses and carer's empirical knowledge in order

to categorise challenging behaviours under definable labels. I suggest that these labels offered clarity and order to carers trying to manage emerging symptoms from their person with dementia. Odd behaviours that challenged social appropriateness or defied a carer's ability to soothe them were made meaningful in conversations that assigned a label to them, thus marking them as expected and correct in light of the particular progression timelines each dementia type presents. Examining how and why dementia types are hashed out in-group is aided by considering the usefulness of stereotypes as cognitive 'schemata': that which helps people to map out their worlds and anchor themselves within it (Neisser 1976: 53-4). Mapping out all the variable information on dementia and then figuring out what was stereotypical or could be expected by different dementia types allowed carers to anchor themselves to subsequently informed timelines of further potential dementia symptoms and caretaking duties. New carers always listened avidly to this plotting work, often writing notes, and many remarked that they felt 'a bit dumbstruck' and 'relieved', underscoring the importance of this work, and the relief associated with 'hav[ing] a name for what's wrong'.

While dementia types and labels were brought up regularly in carer group settings, I do not wish to give the impression that carers' interpretations of these

types were able to entirely side-step the ambiguity of biomedical renderings. 'Not being sure' about what fell under certain types, or which label was most appropriate to a new carer's experience was key in prompting re-hashings of 'what is which type' and questions the usefulness of types at all. Lippman (1947) described stereotypes in public opinion as devices that simplify complex phenomena into uniform 'facts', but which do not support ambiguity or paradox. This is pertinent in considering through how carers unpack the stereotypes of dementia which clearly mark certain behaviours or challenges and particular dementia types. Lippman ties stereotypes to being able able to choose a course of action and reaction. He suggests that moving past stereotypes to see a situation to consider new ideas might result in inaction, because the clarity afforded by stereotypes is then taken away, and the way forward is made unclear. I argue, however, that explorations beyond the stereotype are the 'active movement' that Lippman suggests would prevail if stereotypes were dropped. Carers' interrogation of their working knowledge of dementia type is deeply active: instead of resting on biomedical ambiguity, carers assemble their diverse experiences to instigate actions of care.

In allocating dementia labels through the collectivization of group members' working knowledge of 'how it [a certain type of dementia type] plays out', carers

anchored themselves within a group that 'understands what really goes on [in providing care for a person living with dementia].' This is important, because the working knowledge of dementia type not only normalises certain behaviours, symptoms, declines, or moods (to an extent), but also offers insight into 'what to do!', a direct response to the often pervasive feeling that dementia is 'confusing' and 'you can't quite be sure what's coming.' It is this guidance on how to 'manage' a person's symptoms as well as the stress of caring for someone, that goes beyond the knowledge offered by medical 'experts' with whom many of my interlocutors had met before and after receiving a diagnosis. Here we see that lay knowledge of dementia type also includes the expert knowledge of 'tinkering' (Mol 2008). Dementia types labelling, as a tool, was continually re-adjusted in light of new empirical data brought to the group, and to meet the needs of carers who 'need a better idea of what's going on.' As Moreira's work in an English memory clinic shows, 'the creativity of tinkering, involves the collective. It shifts and fosters the distributed links that make it possible to 'get on with it'' (2010: 135). While Moreira is referring to collectivities formed around patients to extend their scope of action, the importance of the collective rings true in support group settings exclusively for carers learning to manage their own caregiving responsibilities as well.

Revisiting Pols' work on telecare devices, I consider her description of the

opportunity such devices created for 'shared experience' among COPD patients to frame how carer support groups similarly create a way to produce and make use of 'shared experience'. Pols describes how patients used the interactive and communal space created by telecare videoconferencing to better understand the ambiguities and probable occurrences of their illness through conversation with others also diagnosed with COPD. Telecare devices '...may help patients identify what is 'me', what is the 'illness' and what is something else. The exchanges help patients shape ways of living with their condition and anticipate how their bodies will react to the circumstances...' (Mol, Moser, and Pols 2010: 185). While Pols' work was about patients themselves, and with an entirely different illness, I suggest that carers of people with dementia also took advantage of 'shared experience', but in perhaps more complicated ways.

The fact that dementia type motivated action and discussion of strategies to prefaces discussions in subsequent chapters. Carers sought to understand delineations between their person with dementia and their illness (explored further in Chapter 2) and worked together to assemble management strategies for the present and likely future challenges which dementia creates (see Chapters 3, 4, and 5). However, they did so not only to understand the illness trajectory of their person with dementia, but also to 'shape ways of living' for themselves as

their caring responsibilities increasingly impacted upon their lives. The 'problem' of the ambiguity of dementia, what exactly its prognosis, symptoms, and challenges are, are 'solved' by mapping group members onto probable narratives based on type, but also within social networks that will need to be called upon as caring for someone with dementia becomes increasingly challenging.

## **Part Two: Support groups for people living with dementia**

I quickly got into the backseat of Claudia's car after she pulled to a stop, picking me up on the way to a support group for people with dementia. By then I had been a regular volunteer for about 6 months. My quick 'hello' was a short pause in the conversation between Sarah, another Alzheimer's Society staff member, and Claudia. They were discussing conversations they had had over the past week with various members of the support group to which we were driving. Claudia described her latest efforts to contend with the growing waiting list for the group, and they both picked up an oft-repeated line about the need for more support groups for this cohort of people. I interjected with a question about obstacles to starting new groups, and they highlighted the difficulty of securing long-term funding to ensure the sustainability of the current group, let alone start new ones. Their discussion turned to the recent passing, and imminent implementation of

the Care Act 2014. The Act had passed in recognition of the burden experienced by informal carers of people living with substantial health issues, of all types. Local Authorities had been given implementation guidance to provide more support services for carers, resulting in more funding being given to organisations like the Alzheimer's Society for carer services. Such funding often brought with it specific stipulations of what counted as 'support'. A number of the staff members I spoke with described feeling limited and not able to follow their own judgment in deciding what sorts of services their borough branch was able to organise.

After a 10 minute drive, we arrived at the community centre and began setting up the room for the meeting. Chair in hand, Claudia told me that, 'It's been quite a job figuring out how to convince funders that groups for people with dementia, or services that cater to them, are important as well – even if they don't seem to obviously cater to respite, or the like, for carers.' I helped Claudia to set out the rest of the tables and chairs and we spoke more about this hidden side of her work, in which she has to try to set up services that meet both funders' stipulations and what she feels her clients wanted and needed. As we talked, members of the support group began to arrive.

By this point, I was familiar with many of the members of this particular group,



and said hello to everyone as they came in. They asked how I'd been, and moved around the large table in the middle of the room to find the seat they sat in every week. I set out plates of fruit and biscuits and began filling drink orders from memory. Hermione joined the group, and I spooned three sugars into a cup of tea, adding just a splash of milk. Michael followed John into the room, and I added coffee to two cups of hot water, stirring sugar into one and milk in the other. As with carers I came to know in other groups, I memorised drink orders, but in groups for people with dementia, this became more of a pronounced game that we played at the start of the meeting.

A year into fieldwork, I was almost infallible. Only the newest members stumped me. I apologised to one such member, exclaiming 'Anthony – I'm sorry! I can't remember what you like, I know no milk – but is it tea or coffee?' and got a chuckled 'Tea, my love!' in response. As I passed out a last cup of coffee to a woman settling in beside me, Claudia quickly introduced me to the group, as she did every week, saying, 'This is Lilian again, doing her PhD research. She'll be sitting in and taking notes again if you're all happy?'. She also welcomed Anthony back again to the group. Nods circled around the room and I settled into my back corner with my notepad.

The group got underway with Claudia saying, 'I'm glad you all came today in the lovely weather!' while passing out a few different handouts. One had information about an anti-scam service for elderly people running in the borough, while another had information about upcoming meetings dates which were earmarked by Claudia as 'for the diaries'. She then passed out a sheet of paper, calling it a 'memoir activity', which had a list of questions about people's lives. Questions varied, such as: *Where did you grow up? What was your greatest moment of accomplishment? What is your family like? Who has had a big impact on your life? Do you have children?* After about 10 minutes or so of people scribbling in answers, myself and staff included, she asked if people in the group 'want to start off with what we've done for the last few meetings – reading from the book by people with dementia?' People around the table nodded with a number of audible 'yesses'.

Pulling the book *Welcome to Our World* (Jennings 2014) from her bag, Claudia said, 'OK, well, I've had a look through and found a chapter I thought would be interesting' and began reading for the next ten minutes. Nearly everyone in the group became still, but a few continued to write down a few lines on their sheets, before pausing to watch Claudia as she read the chapter in which a man wrote about his life, his career as a solicitor, and the creation of a firm of 'transcendental

meditator lawyers'. The room was quiet, punctuated by soft scraping noises as someone reached for another biscuit, and a few smiles when Molly, a woman who had been attending the group for some time, nodded off to sleep for a moment.

After the chapter was finished, Claudia directed the group back to the memoir sheets we had written on before the reading exercise. She then invited people to share some of the answers they had written down, 'It doesn't matter which one!' The group as a whole revelled in this, and almost everyone eagerly spoke about their memories. Henry spoke of having lived abroad as a visiting physician and being sure he only got the job 'because my wife had had triplets – and I think they [the school who hired him] wanted to take a look!' and explained that he was still friends with many of his 'old colleagues - we get together for lunch a few times a year'.

Another member, Sandra, told the group about the deep fulfilment she gained from her previous occupation as a child psychiatrist. With some difficult and halting words, she recalled her experience treating a '...young boy who had been taken away from a terrible, uh, home life...poor thing, and he wouldn't eat, always kept his legs drawn up.... his stomach covered. You know... [places hands over her own stomach and grips her flesh]...The other doctor and I were with him for days,

weeks...we had to put him on...on...food through a tube, but slowly...to look at me, and talk to me after ages! We ate an apple together after drawing, and oh, it was, it was – [flashes hands open and closed]...seeing him have something to eat and to know I'd reached him...it was, was – wonderful!

Maria described her experience escaping from Germany to England when she was a teenager: 'And they [those who welcomed her to the UK] were so nice to us! I couldn't believe it – we were so hungry, and they gave us such lovely food and new clothes. We joined a church there, and they were such good Christians to us. They really took us in, and after how long we'd been trying to leave Germany it was just so, so...wonderful. I thanked God every day.'

Gerald recalled his childhood growing up in Yorkshire, '...and really that's where the best people are – when you're in York, you know who you are', going on to describe his fairly regular visits to his siblings, nieces and nephews who still lived in the area he was from.

Molly recalled her own years as a young nurse in the RAF in Northern Ireland. Maria teasingly asked her if she had 'met any handsome pilots' to which Molly replied, 'Well, yes, of course – when I wasn't on duty! [Molly and group laughs]...it

was such a nice time, considering, we all had so much to do, and met so many people.’ Molly was teased good-naturedly by other members of the group, most notably by Maria who elbowed her and asked, ‘So many people, huh?’ to which Molly slyly replied, ‘...I did have a few boyfriends before I met my husband!’

Greta told the group about her children’s childhood in South Africa, where she and her family had lived for a decade: ‘Oh it was warm there – the children were always running barefoot...’ While she missed ‘all the sunshine!’ she described the small garden she keeps, which ‘does well despite our miserable weather’.

Members of the group listened attentively to one another and often enthusiastically clapped and laughed in response to many of the stories shared. At the close of the group that day while packing up, a few people mentioned, ‘That was so nice!’, ‘It’s so nice to have a chance to learn about each other, isn’t it?’, ‘There are so many interesting histories in this group!’ and, ‘Yes, people have had all kinds of experiences – and you’d never know it just by looking at us!’

\* \* \*

The vignettes above were typical of a support group meeting, although the activity at the centre of each meeting often changed. What we can see is that in

support groups for people with dementia, people gladly and enthusiastically shared biographical information with one another. Indeed, I chose to describe this particular morning session because biographical accounts were some of the most common in these groups, regardless of the central activity, as well in other Alzheimer's Society service settings. Here, the importance of biographical information in constructing identity emerges. It also shows that constructing narratives through storytelling is implicated in the formation of self. However, while understanding that biographical information is important for identity construction, this does not in itself clarify what counts as biographical information or which aspects of a person with dementia's life are most constitutive of identity. This Part Two section is dedicated to exploring the ways in which my informants with dementia constructed narrative accounts and what they contained. I show that these informants described their lives as a chronological unfolding of events, but in contrast to carers, they did not tie this to timelines informed by dementia or medicalised information. The people I worked with who had dementia drew on different sources than carers to craft their identities, instead highlighting accomplishments and social roles outside the context of dementia to explain who they were.

I situate this section within other research on narrative and people with dementia,

and support groups for people with dementia. The importance of biography and narrative in anthropological research on people living with dementia (Kaufman 1986; Sabat and Harre 1992) and their 'maintenance of the self' (Basting 2003; Harris and Sterin 1998; Mills 1997; Robertson 2014; Ryan et al. 2009; Saunders 1998; Surr 2005: 1720; Tolhurst et al. 2017; Vittoria 1998) are far from new findings and are corroborated by my own. However, in my research, narrativity was often something that was *strived* for, and not necessarily a 'natural' form of communication. The 'naturalness' of narrative is an assumption which emerges in work on narrative in contexts of dementia through emphasis on its therapeutic value and as a form of communication to which people with dementia can be supported to return. My examination of narrative in dementia contexts also differs in that the majority of my data derives from observation of people with dementia speaking with one another. Other methods mostly have involved conducting interviews with people with dementia individually, in dyads with a family member or in observation between people with dementia and care staff. In contrast, I am interested in what occurs *between* people with dementia in settings in which they are often encouraged to direct the flow of conversation. As such, this section also contributes to the small body of research on support groups for people with dementia. The majority of this research has aimed to examine outcomes related to depression, wellbeing and efficacy (Toms et al. 2015), which is not my aim. Only

two studies have centred on support groups facilitated by the Alzheimer's Society (Dobbs et al. 2009; Mason et al. 2005). Mason et al.'s qualitative approach was to 'investigate the mutual support processes' provided by and found useful by these groups (2005: 104) which more closely resembles my own focus. In line with their findings, I also demonstrate that support groups were not emotion-focussed and centred on direct discussion of dementia, and its emotional and practical impact. The material to follow highlights that for people with dementia, support groups were treated, and valued as, an opportunity for social contact and conviviality, that at the same time was animated by a complex interplay of diverse personalities. I build on Mason et al.'s work by highlighting how narrativity informed people's sociality in the groups and that direct discussion of dementia was not deemed a requisite element in the accounts they shared with others or their sense of self.

In Clare's research in southern England focussing on people with early stage Alzheimer's awareness of their condition (2003), she positioned her research participants on a continuum of 'self-maintaining' to 'self-adjusting'. 'Self-maintaining' refers to attempts to normalise and minimise their difficulties in order to maintain a continuity of self, and 'self-adjusting' 'consisted of attempts to confront the difficulties and adjust one's sense of self accordingly' (2003: 1021).



The material in this chapter might, on the surface, seem to suggest that my interlocutors with dementia resided on the 'self-maintaining' end of Clare's continuum. However, I suggest that their discussions show that efforts to normalise and minimise difficulties are entangled with efforts to also 'confront' one's dementia. Further, I also suggest that adjusting one's sense of self was often sought as *a way by which* to maintain a continuity of self. My suggestion is informed by Kaufman's claim that "[c]ontinuous restructuring [of identity] allows individuals to maintain a feeling of unity about themselves and a sense of connection with the parts of their pasts they consider relevant to who they are at the present" (1986: 150). These re-adjustments also link to Kaufman's suggestion that one's 'enplotment' in the world around them is continually evolving, and it is one's inability to keep track of these changes that poses a loss (1986). The interplay between adjustment and continuity which this research highlights links to why, perhaps, my informants with dementia did not focus on 'confronting' their dementia.

### *Dementia as a non-element of identity*

It was only in Claudia's readings of material from books and Alzheimer's Society material, that group meetings involved repeated, direct allusions to dementia by

name. People with dementia resisted the very word 'dementia' and instead said that they 'wish[ed] it was called something else, something less, oh – clinical. Makes it sound so horrifying.' People in these groups saw medical understandings of dementia as misleading, and Toni, a newer member of the group said, 'Not too long ago they didn't even call it dementia, it was just ageing!' This touches on Lock's research on the confluences made between normal ageing and dementia (Lock 2013) and points to other discussions about the fairly recent medicalisation of senility (Cohen 2003). In one enthusiastic conversation, group members traded names of 'what I wished people called it [dementia]' and what 'I tell people', suggesting that 'memory problems,' 'old age...a little trouble remembering' and 'brain injury' were more accurate depictions of their experience.

In the following chapter I more closely examine the reasons for side-stepping direct references to dementia and purposefully making use of the ambiguity between old age and dementia, as well as the social risk involved 'with actually telling them Alzheimer's'. Here, it is important to note that one's status as having dementia was not seen as significantly constitutive of identity. This stands in contrast to other people with dementia who sought out medicalised information about their disease and affiliated closely with the disease. These contrasting accounts are described in formal auto-biographical narratives, such as McGowin's

book *Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's* (1993) and Davies' *My Journey into Alzheimer's Disease* (1989). Although fictional, the most popular example of this depiction of people with dementia living in full acknowledgement of their disease may be *Still Alice* (Genova 2007), which was later turned into a film (2014) of the same name. Much rarer are works such as Henderson's *Partial View*, in which he writes 'I may not know all the time what I'm talking about, but I, damn it, still I can talk' (1998: 3), and includes fragmented prose that aims to represent the experience of living with Alzheimer's in its episodic reality, divorced from chronology (1998).

Instead of relying on direct engagement with medicalised knowledge about dementia, my informants living with dementia presented themselves as people living their lives 'in much the same way'. They often described their present by pointing to its similarity to the past through descriptions of continuity of their familial and social lives. Such continuity of self through time and the lack of emphasis on dementia offer an interesting consideration of Kaufman's 'age-less self' (1986). They align with her findings that '[t]he old...perceive meaning in being themselves in old age' (1986:6). However, they also suggest that for many, their diagnosis or onset of dementia was not what brought about significant conceptions of being 'old', at least as was apparent in narratives told in group

meetings and individual interviews. In fact, many did not remember the event of their diagnosis or consider it a particularly meaningful event (explored further in the following chapter). Instead, old-ness was established through an accounting of 'all that's happened', such as having retired years earlier, or having grandchildren.

The prevailing murky and ambiguous conflation of old age and senility can normalise experiences such as memory loss and blunt their gravity as a serious illness event. The absence of dementia from the narrations which dementia support group members presented in the groups mimicked the omissions of the effects of dementia from the actual prose of books written by people with the condition (Basting 2000). Inclusions of wandering tangents, difficulties with spelling, and organisational structure, were corrected with help from family in the published narrative representations (i.e. the books mentioned earlier) of people with dementia's experiences. The prose did not belie the full experiences of dementia or represent dementia forms of 'narrative thinking' (Kaufman 1986), even if the condition was the centre of its content. I argue that my informants living with dementia strove for similarly 'normal' ways of talking about themselves that did not 'give away' their dementia, and underscored this effort by barely speaking of dementia at all. I suggest that ambiguity is made use of and even

deepened to create distance between 'who someone is' or 'what you do' and the disease of dementia. People stressed that their identity did not rely on dementia, that they 'weren't the diagnosis', often remarking instead that 'We're just a bunch of old people!' This differs from the central defining role which dementia played in carers' discussions about themselves, and explanations about why they attended support groups, and what their present challenges were rooted in.

So, if people with dementia's sense of identity or self did not rely on dementia, and instead crafted at a distance from it, how, then, was it made, or iterated?

*Getting to Know You, and What You Can Do: biography as the source of identity*

As seen in the vignettes in Part Two, this cohort of people strove to introduce themselves by way of anecdotal biographical accounts. Biographical narration conceived as a route to a 'coherent sense of self' (Fivush et al. 2011:1) is common across disciplines. The accountings in these groups were a way for members of the group to come to know one another through a marking out of what the teller themselves saw as the specificity and uniqueness of their individuality. For example, an animated conversation erupted in a support group discussion on a different day than the one described above, when Molly mentioned that she had

been 'a nurse in the RAF during the war years.' This prompted others in the group to describe where they had been and what they had been doing during that time, and to compare and contrast their experiences. Group members listened avidly to one another's stories with encouraging comments such as 'Isn't that interesting?' or 'You've been everywhere!' marking out the novelty of one another's lives.

Group attendees also often went further to establish a continuity of self over the life-course by pointing out a continuity of personality or skills. For example, Molly mentioned that after the war she '...took care of my family, which is pretty similar [to being a nurse], really! And then the grandchildren!' And another member commented on a man's meticulous and tidy habits when eating the fruit and biscuits laid out at meetings as 'a sign that you were an anaesthetist – no mistakes allowed there!' In these examples, the specificity of *who* a person was, was made through the telling of distinctive and personal life stories that established the continuity of this individuality, and self, as independent of chronological age.

My memorisation of everyone's tea and coffee orders was a recognition of the importance of this specificity, and evokes incidences that Mol witnessed in her research on food in care homes (2010). Like the food assistants preparing breakfast in the Dutch long-term care facility where Mol spent time, I too 'get to

know people' by anticipatorily preparing tea based on what people 'like', as per their specificity (Mol 2010: 215). Attention to this detail, similar to Alzheimer's Society staff members' recognition of members' preference to sit in certain locations, 'made room for individual specificity' through a recognition that attendees had a 'choice' of drink or position around the table (Mol 2010: 220). I draw on this framing of choice and individuality to emphasise how practices within the support group acknowledged members as separate persons with a defined point of view and intent. Following the norms of the group, I purposefully made an effort to recognise my interlocutors' individual preferences, preparing teas and coffees to order not simply as a way to ingratiate myself, but as a way to express care and recognise their individuality. My preparations often prompted questions from those arriving to the meeting about 'what [I'm] having'.

Reactions, positive and sceptical alike, to my insistence on decaffeinated coffee or herbal tea were acts of reciprocal recognition of my own individuality, narrowing the gap between myself as volunteer/researcher and group members as service users, but also establishing one another as separate. These exchanges were a way to 'enplot' (Kaufman 1986) one another in the world around us, and mirrored how members' telling and listening to each other's stories outlined not only *who* a person was, but also *who they were to others*.

About halfway into my fieldwork, I was invited by Alzheimer's Society staff to help, as a volunteer, to start a new support group for people with dementia. This group was forming in a borough whose neighbouring groups I already attended regularly. I agreed readily, looking forward to meeting and observing a new group to see if my notion that support groups subtly taught their members to iterate descriptions of their lives in similar ways held true. I was interested in what a group of people who were meeting each other for the first time, co-creating the norms of a new group under the guidance of an Alzheimer's Society, would talk about, and how they would present themselves. On that first meeting in a sunny, cosy room in a seniors' community centre, the members of this small, inaugural group spoke about their families, previous occupations, and addressed the topic of dementia obliquely. They were true to the form I had come to expect in other groups; at this first meeting, the entanglement of past occupation and family life became immediately apparent.

By way of introduction, two members of the group, Ethel and Fred, told the group that they lived with their respective spouses. Fred, a man resembling Santa Claus with a reddened nose, and paper-white beard and hair explained:



'We've been married for almost 50 years, soon after I'd finished my certification and started working. Had children young too. Our granddaughter wasn't getting along well with her mother for a while, so she stayed with us till she finished school. I was working then, out of the house most of the time, but we've always had people in the house, even if it was tight. No children now, but then my wife got dogs!'

Ethel nodded along to Fred, and similarly explained that she and her husband had been married for quite some time, and had lived in a few different countries following her husband's job before settling in the UK for the past twenty-five years:

'He was high-up at the end of all that, earned the chance to settle. I had always picked up work wherever we moved to, sometimes teaching piano or secretarial work. We never had children, but we have nieces and nephews. They live in America mostly, and we lived there for a while ourselves, and we try to go over every few years.'

The third group member, Lucy, a woman in her late 70s, explained that she lived with her daughter and daughter's partner. She had moved in with her daughter recently from another part of London, where she had lived for the previous 40

years, and had owned a business with her late husband. She told the group about the difficulty she and her husband had had 'toward the end'. Lucy explained:

'You know, we spent our whole life running that business. You don't get holidays when it's your own – up early in the morning, late nights – anytime you're not working at it, you're not making money. No simple payslip. And the last years, it was so much more tiring; we were worn out, I think, having done it for so long, but we couldn't stop working because we'd had a son – we don't talk to him anymore, not for fifteen years at least – he took all the money from the business – just took it and left, can you believe it? I think it must have been drugs. We woke up one morning and the accounts for the business were empty. Oh, it was awful; we were hoping to retire soon before that, but we had to put in most of our own money to save it really, so we never got a chance to stop and I think that's what did Clark in, really. It was too much for us at that age, the stress of it, and what our son did to us. Rotten, really; I still can't believe it. How could a son do that? No responsibility. Thankfully, our daughter was there and she helped, bless her. But I still just can't believe it, really, can't. Clark's gone, bless, and now I live with my daughter, so she's helping again.'

Lucy repeated this particular story once more over the course of the meeting, and frequently made comments, 'rotten' and 'still can't believe it' a number of times over the course of the session, and in sessions over the following weeks. In Lucy, Fred, and Ethel's stories, the importance of telling people what you had done and what you had been responsible for is obvious. Fred spoke about his having work, and alluding to the family he supported with his job. Ethel highlighted how her, and her husband's residence had been dictated by her husband's work and the ways that she herself took on employment, perhaps instead of raising children. Finally, Lucy's unhappy story, perhaps best of all, exemplified the relational context of familial and 'productive' responsibility that people with dementia drew on to construct narratives of their lives and explain who they were. She mourned the misfortunes of her life and death of her husband in a narrative which pitted her role as an independent, capable business owner against a description of her son as an irresponsible, thieving member of her family, who did not contribute and instead only took. People were who they were, based on their ability to be responsible for particular things.

The importance of constructing a role based on who one is to other people was a pervasive concern in groups for people with dementia. Akin to other research

with people living with dementia in the United Kingdom, my informants also identified that relationships to others, and '[s]ocial roles related to work, being part of a family, caring for others and being cared for, were particularly significant for self' (Surr 2005: 1720). Notably, my interlocutors with dementia never referred to a family member as their 'carer' and avoided positioning themselves as person who was completely dependent on care, a topic explored further in later chapters to show that these relational connections are constructed through histories of being responsible and serial exchanges of care. Notably, the importance of this kind of identity-making through biography was not only relegated to people with dementia.

On the rare occasions when carers spoke about themselves personally in casual settings, such as lunchtime at a Caring Café, where conversations were less confined by the aims of the carer support group, carers also described their occupations in conversations. 'My wife and I had a small business', 'I worked for the NHS, in one of the administrative departments', or 'I raised the children – homemaker I think they call it now!' are examples I overheard in conversations aimed at getting to know one another. What they do, or did, in terms of work and, more abstractly, what their responsibilities in life had been featured strongly in their narratives and played an important part of their identity. Similar to people

with dementia's accounts, I argue that people focus on the responsibilities that come with an occupation, and what position that role puts one into in relation to others.

When carers described what their responsibilities had been in the past – be it occupational or familial – it was often in contrast to their current and recent caring responsibilities: 'now, I'm a carer – look after him all day', 'it's almost like having two jobs, I leave in the morning to go to work and then come home and let Sara [the professional, hired carer] go home and look after her at night'. Regardless of whether they are speaking about occupations past or present, carers highlighted *what* they did as an important way to signal the significance of their role, and its import to their identity. The same is true for people with dementia, and, in fact, a common complaint I heard was about their frustration at 'not having anything to do really' or 'it's almost as though you just become useless once you're old'. Having something to do that was considered meaningful was important not only in and of itself, as a part of 'living well' and ageing 'successfully' (Kaufman 1985; Lamb 2014): continuing engagement in meaningful social activities and contributing to family and society was important because it gave people something to talk about. The importance of this status was illustrated by ways in which groups respected and took note of each other's accomplishments, as well

as the moments when group members, particularly carers, took stock of the waning of one's ability to be responsible for things and a contributing social subject.

Important too, is the ability to know and iterate the *when* of these relationally meaningful events.

### *Narrative as temporal order*

Beyond being a method by which a person establishes their identity, biographical narration also gives temporal order to experience. Symptoms of dementia often make 'normal' reckonings of time confusing, which in turn creates an atmosphere of temporal disorganisation. In many public depictions, people living with dementia are described as having a propensity to become 'lost' in time and to experience temporal disorientation. In these ways they stray from embodying notions that 'all normal non-pathological human beings are naturally Narrative and also that Narrativity is crucial to a good life' (Strawson 2008: 429). This is because normative western constructions of narrative rely not only on the recounting of memories, but their presentation in ordered ways in which they neatly belong to the past. Temporal orientation and cognitive capacities to

remember, plan and enact order are at the heart of what dementia dismantles. I suggest that one reason for disorientation being deemed problematic when people with dementia cannot remember events, or what happened when, is because stories that are temporally disjointed are not seen as valid narrative. This draws on work on narratives in health contexts which proposes that 'narrative implies a sequence of events connected to each other through time' and casts a 'chaos story' as a problematic and an unsustainable state to be resolved (Frank 1995: 98).

In ways similar to how crafting the timelines of disease progression or sequences of care responsibilities interject a chronological ordering to the experiences of carers' lives, biographical narration also provides a normative temporal framing to the lives of people with dementia. This group's emphasis on biography established the prevailing correctness of a linear progression of time, with past events having occurred before now, and future events occurring after now. For example, both the memoir activity, and the chapter read from the book, organised experiences into such a chronological sequential format. Even temporally open-ended anecdotes inspired by prompts such as, 'write down or tell us about a time when you were really surprised by what someone did' were then chronologically grounded with follow-up questions such as 'When was that?' or 'Did that happen

before you moved to England?’ Drawing from western philosophical work examining personal identity, we see that if narrative is to be constitutive of identity, it ‘requires that an individual conceive of his life as having the form and the logic of a story – more specifically, the story of a person’s life – where “story” is understood as a conventional, linear narrative’ (Schechtman 1997: 96).

In ironic and earnest tones alike, both people with dementia and carers sometimes referred to their experiences as part of a ‘dementia journey’. I often heard the remark that they ‘just live one day at a time’ when describing particularly difficult circumstances. This implies that while their ‘present’ is confusing or ‘hard to believe’, and is experienced in a state of temporal suspension, it is nonetheless sequential. Moments of confusion followed one another, chronologically, constructing a linear narrative of ‘journey’ with a starting point and end. How the temporal confusion of the ‘present’ is dealt with in daily life is explored in greater detail in Chapter 3, but here I argue that support groups for both cohorts worked to establish temporal framings that are chronological, linear and progressive in response to the temporal confusion and ‘episodic’ moments that dementia creates. The memoir activity that the meeting described centred around was not accidental, and instead underscores notions that promote the therapeutic value of narrative in dementia contexts to help construct identity and order experience



(Birren and Cochran 2001; Clark 2001; Ryan et al. 2009). Indeed, I attended a dementia product 'pitch' at an Alzheimer's Society Caring Cafe which featured a new 'reminiscence tool' [unnamed for anonymity reasons] aiming to

trigger memories of a person's life – through pictures from periods of their childhood, or a song – so that they can tell us [care staff and family members] the stories they've forgotten. We've trialled it – and they [people with dementia] just light up- talk about things they haven't in years. And then software saves the collection [of memory triggers] that got them going, so it can be used again and again to spark the dialogue.

This tool and the group activities aim to bring people back into the fold of normative narrativity, and have their experiences be meaningful to others, thereby allowing their individuality and agency to be recognisable, rather than suspect. Consider for example, that although Molly fell asleep during the chapter reading, others asked her questions and encouraged her to take part in the memoir anecdote conversation afterwards.

While a striving for normative narrative framings of their lives was a clear, this aim and perspective on experience was not absolute. I often heard the refrain from both carers and people with dementia that they are 'just try[ing] to make sense of what's going on now', echoing Strawson's concept of 'episodic' experiences in which conceiving of the past or future cannot be achieved (2008). For example, in an interview with Emily, who is living with dementia, she explained to me that when she had

a day – when you wake up just not quite all there, a bit muddled but also a bit tired, and just don't want to make the effort to get...straight [to strive against an encroaching confusion caused by dementia]...so I just don't really. I stay at home, and don't try to rush around to get things done or meet people at certain times, and...instead put about at home, doing this, doing that, not really worrying about *plans* – those days aren't every day, so it's alright sometimes I think.

During a support group for carers, a carer named Meredith described how periods of her time caring for her mother was

like a fog – just a daze, limbo and I didn't try to come out of it, really, but just entered her [her mother's] world and let go of any expectations of how the day was going to go or what she would remember, and...and I think it helped...[Meredith gazes into space, and pauses, as if re-experiencing the 'fog' she mentioned]...it was easier somehow, less effort to try and hold it – really the bits that weren't so important-together...if I tried to always make sense of what I was doing [as a caregiver], you know, how I might have when I was working, I would have gone crazy. So, I just went with it [the feeling of limbo], and I was able to slip into this space of calm...and sometimes a few days just sort of slipped by and I didn't try to keep track of them the way I normally would have.

These examples show that subscription to narrative as the best ordering of experiences past, present and future was uneven across my fieldsite. Such

accounts in support groups and interviews were rare, but not inconsequential. They signal that the totality of people's experiences over the course of living with or alongside dementia do not fit into or make use of stricter forms of narrative framings. A number of my interlocutors stepped outside of efforts to maintain a sense of linear sequence in their experience, or narratively account for all the events in their lives. As the statements show, this was often a conscious choice in order to gain a sense of calm. Taking seriously their feeling that 'letting go' and suspending chronologically ordered plans was 'easier', underscores Strawsons' challenge that Narrativity is not the natural, organising feature of (non-pathological) people's experience. Not 'keeping track' of events and days also echoes work conducted by Day with sex workers in London, examining the interplay between temporality and identity (2008). While the connection between her interlocutors and my own might seem tenuous, I draw on her findings because her informants were often careful about including and leaving out certain spans of their lives in narratives to consciously craft their identities and life trajectories. In Emily's case, 'not making the effort' to keep track of all her activities or her grasp on time might be protective against an experience of stressful biographical disruption caused by 'confronting' her disorientation. Similarly, Meredith described not taking stock of her activities as a carer to not 'go crazy', thereby protecting her affiliation with the role. These women's accounting of periods when

they do not try to maintain a grasp on 'what's going on' seems to become a part of their sense of self, not threaten it. This approach is one which appears to entangle aspects of Clare's 'self-adjustment' and 'self-maintenance' stances (2003) in that 'confrontations' of dementia and deft re-directions of one's attention are both tools that allow a person to manage the 'symptoms' of dementia. These tools are seen as an important part of adjusting to life with dementia, and fit in with efforts to support a continuity of self.

Furthermore, the experiences shared by these two women also touch on the importance of meanings and experiences not easily translated into verbal narrative forms, particularly metaphorical meanings and renderings of stories. Meredith described her 'daze' 'like a fog', and Emily used the phrase 'to get straight' to refer to efforts to overcome disorientation. Dementia researcher Surr sensitively points out that not recognising 'potential metaphorical meanings might lead the listener to make assumptions that the person with dementia is time confused and living in the past, recognising only their cognitive losses' (2005: 1728). This warning also highlights the importance of exchanges such as Maria's and Molly's playful dialogue referencing youthful promiscuity, or Sandra's stilted description of treating a young boy, aided by embodied gestures to relay some of the events of her account as well as the emotional import of the experience.

Surr points out that only interviewing people who were verbally articulate was a limitation in her own research (2005). Capturing Sandra's accounts (as well as the accounts of others with aphasia, featured in this thesis) addresses concerns about a lack of discussion and inclusion of embodied forms of communication and narrative. This point will be revisited over the course of this thesis because in attending to narrative, I aim to consider accounts that fall outwith normative framing but emerge in other forms, particularly those which gain deeper meaning as people with dementia's verbal communication and cognitive capacities change.

*Support groups are not only a place to come and tell stories*

While I have discussed the ways in which many in the group saw the meetings as an opportunity to socialise and get to 'know other people', members also acknowledged another underlying motivation for attending the group which more closely reflected its official remit. Claudia's and Sarah's conversation at the start of Part Two, exemplified Alzheimer's Society staff members' need to follow specific stipulations and guidance in organising support groups for service users. Other research on support groups has recognised that staff members are important facilitators with a motivation to guide discussion on dementia-specific topics, at least part of the time (Toms et al. 2015). While this held true in my site,

the facilitators I observed appeared to be much less directive than facilitators described elsewhere, preferring to prepare a topic of discussion for the day's meeting and then letting the discussion evolve organically according to the interests of the group. Attendees and staff alike described the purpose of attending as 'a good chance to keep active' and to trade advice about help to 'keep track' of events, appointments and 'other things.' Discussions in these groups centred more generally on a sense that one can be and should be prepared for challenges and confusion created by 'problems with memory', and revealed task-based timelines. These differ altogether from the timeline of specific dementia progression constructed by members of carers' groups. They featured concerns about 'what someone should be thinking about' in terms of both broad and specific tasks. Some examples include eventually 'giving up driving', instituting a calendar or diary system, ordering a bus pass, continuing with or starting to exercise, writing a will or medical directive, visiting friends and family, and applying for various services or benefits from the local authority. The specificities of these tasks are explored in greater detail in following chapters, but here I note that these tasks were not strictly ordered, though the urgency of some, such as official legal paperwork (Chapter 4) placed them as necessary to complete 'soon, if not already'. Task based timelines were deemed applicable to most everyone. Small adjustments to how quickly certain to-dos should be completed

were made, often based on people's familial circumstances or how much help they felt they needed or to which they had access. For example, those who lived alone or whose relatives seemed untrustworthy were encouraged to 'sort out your will' or a medical directive with more urgency than others. Despite these small adjustments, my interlocutors with dementia did not see each other as inhabiting drastically different locations on individually unique timelines. Instead, members plotted one another by the degree to which they had instituted strategies to manage and prepare for dementia, or were living the 'good daily habits' to help keep memory problems at bay.

Support group facilitators aimed to be particularly helpful when it came to such tasks. They were watchful of opportunities to offer to follow-up on tasks, with people's consent, such as making phone calls to GPs, electricians and plumbers, making applications to the local authority, and alerting people to things such as changes to bus routes services users frequently used. One of these facilitators always fastidiously wrote down notes to 'make sure I remember everything' and when I visited the local Alzheimer's Society branch offices, it was obvious that staff members were often making phone calls and waiting on hold on behalf of their clients. Many carers and people with dementia looked visibly relieved at these offers of help. Asking about and noting down these tasks subtly encouraged a

group's focus on dementia and its related challenges, particularly in support groups for people with dementia.

I suggest that attention to loose timelines of tasks in dementia support groups is linked to motivations to maintain the agency and individuality of people with dementia in two respects. The first is that the tasks themselves were often about choice and autonomy – to whom to give one's estate, what sorts of medical intervention were or were not wanted, how to organise one's time to remember appointments, how to travel around town. Secondly, these decisions and tasks should be completed at the proper time, not too late or too soon, so that they steadily maintain a person's ability to 'keep up' with their own self-care and dementia management. This 'keeping up' was considered important because many people with dementia felt surveilled by family and friends who, as one woman put it, 'are watching me to see if I'm not able to manage anymore – I sometimes take the bus even if someone offers a lift because I want them to see that I *can*'. Surveillance is a recurrent worry for people with dementia and examined in subsequent chapters, and underscores other strategies concerned with remaining recognisable as a model of normalised independence instead of becoming subsumed into the role of a cared-for person. While carers groups were centred on crafting strategies centred on supporting a person with dementia, in



support groups for people with dementia, the topic of conversations most linked to the condition centred on ways to account and maintain one's identity, agency and independence.

## Conclusion

Two important points have emerged in this chapter. Firstly, people with dementia and carers are invested in narratives which link to their sense of identity. Secondly, narratives focus attention on how, when, and to what degree 'help' is rendered and needed. Separately and together, these points are tied to my interlocutors' underlying concerns about independence and autonomy, the important elements in constructions of personhood or 'still being there'.

There is a contrast between the ways in which carers and people with dementia approach the topic of dementia. These differences are revealed in how they construct their sense of self and narrativize what they do with their time. While carers attend to dementia closely – naming it and its subtypes, discussing the specifics of its progression and needs, my interlocutors with dementia often worked to distance themselves from 'that kind of chat.' In effect, carers enplot themselves more and more closely in the world of dementia: they are *carers* of a

person *with dementia*, and need to ask other people for help to manage their caretaking. On the other hand, my interlocutors with dementia focus on other topics, working to enplot themselves in a world around them which includes dementia, but is not governed by it. Their identities are based on biographical accounts that highlight a continuity with the past and conversations about how they would continue to manage in the present in light of some troubling dementia challenges. I suggest that this indicates that my interlocutors find that there is more to gain in the skilful balancing of Clarks' 'self-adjusting' and 'self-maintaining' (2003), than in only 'getting real about dementia'.

While my informants with dementia do conceptualise it as a biomedical illness, it does not eclipse their ongoing 'project' of pursuing successful aging and 'maintaining the self of one's earlier years' (Lamb 2014: 41). Entwinements between an 'individualist personhood' as 'good' and 'healthy' and necessary for 'successful aging', as shown in Lamb's research on ageing in Boston (Lamb 2014:1), applies to how my interlocutors view their own aging and constructions of self. Indeed, the people with whom I worked are encouraged to 'live well in later life' and 'live well with dementia' by staying active, staying independent and in their own home by a variety of sources such as the NHS, Alzheimer's Society, and government plans. Such iterations subtly reinforce notions that personhood

is founded in individuality. Both carers and people with dementia plan and mitigate help and care in precise ways to maintain the independence (of both parties) necessary to this successful aging, despite dementia. In addition, maintaining a narrative framing of one's life and identity is useful, showcasing one's 'narrative thinking' (Kaufman 1986) and an important means of retaining independence because it allows narrators to mark their individualism by crafting unique identities relative to other people. Through narrative, an individual who can hold a viewpoint, tell a story, and have the ability to understand and make meaning of the world, becomes visible. Narrative stories also 'reaffirm what people mean to each other and who they are with respect to each other (Frank 2000: 345). People want to be able to tell stories about themselves and others, and have the same done to them in return, as an act of reciprocation. In most cases, a breakdown in narrative continuity threatens people's feeling that they are 'still living my life' with the person they care for, or are being cared for by. This is what makes non-narrativity or purely 'episodic' life experiences, which Strawson (2008) would have us regard as an equally meaningful avenue to identity, so dangerous.

However, at times, narrative styles of cataloguing were suspended if they proved too difficult to maintain and thus a threat to the very identity which narrative is

meant to construct. Episodic experiences can also help to maintain this sense of connection, recalling Meredith's 'go[ing] into' her mother's world, and Emily's contentment with waiting out a period of disorientation instead of asking for help. Overall however, Strawson's view is not held by many of my interlocutors. Indeed, divergences from living a normatively coherent life were only entertained in very particular spaces (discussed further in Chapter 5).

While the people with whom I worked wanted to feel they were on the same 'narrative page' as those in their social world, they also sought space from the suffocation that could result when the stories of their lives became too entwined. The needs of carers and people with dementia are not the same (O'Connor and Morris 1994). This tension is the reason that many carers and people with dementia meticulously chronicle their lives. Narrative-making is a support group-honed practice to keep track of, and find ways to contain, the parameters of a carer/cared-for relationship and its effect on personal independence as greater care is needed and enacted. Many carers felt that their daily lives, intentions and individuality became subsumed into their caring role as a subplot to 'whatever's happening with him [the person for whom they care]'. Subsequent chapters show how carers work to 'tell their side of things' when talking about their past, present and future lives, in order to maintain an independent perspective. The following

chapters also explore carers' suspicions that people with dementia slowly lose the ability to understand the world around them or 'know who they are' because their ways of narrativising their life are no longer recognised. This was alluded to in Meredith's description in which she linked the 'fog' to 'going into' her mother's world. Similarly, people with dementia work to maintain control over their lives by holding on to narrative order, as a powerful way to show that 'I'm still here, goddammit!', like Henderson's claim that he 'can still talk!' (1998).

Considering this chapter's discussions of narrative, chronology, timelines and identity formation, I point out that these elements are similar in that they have a beginning, a starting point. A story begins, an identity is made. In the common reckonings of my informants, the beginning of a story and the origin of an identity happened *before* now, before the telling of the story or the living of an identity. In the next chapter, I examine whether the beginnings of stories or identities do, in fact, reside in the past. Like the usefulness of normative formats of narrative discussed in this chapter, I suggest that it is complex. The 'start' of things – of dementia, of who one is – are, in practice, negotiable, and carers and people with dementia use and rearrange memories of the past in order to help make sense of their current experiences.



## CHAPTER 2: Murky Pasts: Remembering and Experiencing the Beginning of Dementia.

Herein, I build on the previous chapter through a focused investigation of the 'past' as it is described, engaged with, made sense of, and used by carers and people with dementia. I show that in my informants' attempts to describe the past using narrative framings, the past is also rendered perplexing and fluid through these same contemplations. I centre my examination on the event of receiving a diagnosis of dementia and its ramifications on people's identity and social lives. I show that events are re-ordered and their meanings are re-cast to get at the truth of when 'the dementia actually started' and who a person with dementia 'really is'. I argue that the context of dementia proves both difficult and confounding to

my informants' attempts to construct coherent, chronological accounts of their lives and identities with neat, fixed 'beginnings'.

The chapter is divided into two main sections. The first is concerned with how my informants experience the event of dementia diagnosis to examine whether an official diagnosis is meaningful, or not, to my interlocutors. For carers, diagnosis rarely offered clarity to their understanding of the disease or the accumulating symptoms that had prompted them seek a diagnosis for their relative in the first place. I show that for people with dementia, the moment of disclosure of their diagnosis is more significant than receiving it.

The second section explores the ramifications of diagnosis and disclosure on the lives of the people with whom I spoke. Detailing an interview with a carer working to make sense of 'when it [dementia] began', I then unpack how the inconclusiveness of diagnosis caused carers to re-examine past events in which their person with dementia acted strangely, to try to determine if they were the beginning signs of the disease. I then show how these re-examinations work not only to find the division in their past between 'before' and 'after' dementia, but also seek to label odd behaviour as early symptoms of dementia and not as representative of the personality of the person for whom they care. I next examine



the ways in which people with dementia engage with their pasts. I show that biographies were used to construct identities not focussed on a diagnosis status, but instead based on histories of autonomy, accomplishments and family to establish people as functioning, independent adults capable of caring for themselves. These foci explain the hesitation to disclose their diagnosis to family members for fear of being seen as increasingly untrustworthy and unable to be independent. I then explore the ways in which my interlocutors with dementia negotiated their emerging dependence on others for help in managing their dementia by obscuring the link between this dependence and dementia, favouring instead explanations that they need help due to their age. I close the second section by showing that at the heart of people's negotiations of how a diagnosis impacts upon their lives, is a desire to create support networks that preserve the balance of dependence and independence in their relationships, so that they mirror the dynamics of these relationships 'before [dementia] started'.

My data make clear that retrospection is an active process in which the 'starting points' of people's narratives of their lives are re-assessed, moved, and continuously experienced. In this way, narrative and biographical accountings of a person's life, or 'when [the dementia] all started' becomes a project of selection

and reordering in order to craft coherent accounts of identity. Drawing on Day's questioning of the 'metaphors of continuity and integration that are so prominent in biographical idioms and yet so clearly untrue to life' (2008: 173), I also approach my informants' accounts of their pasts as projects that emphasised continuity but at the same time continually re-interpreted past events. As in Chapter One, I draw on Day's work with London sex workers because parallels emerge in the way that Day's informants and my informants with dementia have uneasy relationships with the past. Day's sex workers do not wish to include all periods of time in their biographical accounts, and instead make murky or indirect references to some periods, as a way of constructing personal identities that better fit with who they see themselves as in the present, or the future. My informants with dementia are faced with challenges remembering past events, particularly those nearer to the present, commenting on the 'fuzzy' quality of some memories and referring to lapses in memory evasively. Nonetheless, my interlocutors use particular aspects of their past lives to underscore 'who I am' in the present, and describe 'who I'll always be' as time unfolds. These parallels also exist in carers' approach to the past; while carers focus less on their own, specific personal pasts, 'what happened' becomes murky as they re-remember and re-examine past events to try and figure out 'when the dementia started.'

This chapter also sits in conversation with research conducted with 'high-functioning' people living with Alzheimer's in the San Francisco Bay Area (Beard 2004: 419). Beard's analysis focusses on this group's experience of their diagnosis and identity construction, as does mine, and our findings both parallel and diverge from one another. Beard found that diagnosis was a 'defining moment' in her informants' lives, whereas my material shows that these events were not considered particularly memorable for most of my participants. Our findings converge on the point that 'to tell or not to tell' (Beard 2004: 422) one's diagnosis to family and friends was carefully negotiated because of its significant social impact. Our research also finds that people conceptualised dementia as responsible for particularly behaviours, and while Beard links this to its usefulness in side-stepping blame, my focus here is more on *both* carers' and people with dementia's attempts to maintain a person's identity outwith dementia. Personhood, or 'still being there', is strongly linked to maintaining an identity founded on independence, autonomy and agency. These attributes are also cited as important in other work on personhood and 'successful ageing' in Western contexts (Buch 2013, 2015; Clancy et al. 2015; Lamb 2014), and serve this and following chapters' exploration of how these attributes become entangled with relationality as care is deemed needed, and rendered. In this chapter, I think through the consequences of such a framing of personhood using MacIntyre's

(1999) virtues of independent rational agency to show that people's relationally grounded biographies work to safeguard the balance between dependence and independence. This is done in service of marking the continuity of people's personhood, despite the frequent moments of biographical danger created by a diagnosis and disclosure of that diagnosis.

### **Dementia diagnosis: really such an event after all?**

*"Well, that's what's ironic isn't it? I can't remember it!": the significance of disclosure over diagnosis.*

As explained in the previous chapter, dementia and its dementia symptoms were only rarely directly named in support groups for people living with dementia. However, during a group session that I visited early in my fieldwork, an Alzheimer's Society group facilitator named Sharon asked the attendees, 'What was it like to get your diagnosis?' This was the first and last time I saw an Alzheimer's Society staff member so clearly guide a group's activities toward this topic. It later became clear that she had kindly done this for my benefit. The week before, I had asked her and a few other staff members about service users' diagnosis experiences, as well as the processes by which a person with dementia is referred to the support

group after a dementia diagnosis was made. While their answers mirror the previous chapters' discussion of avoidance of this topic, what emerges in the answer to Sharon's question on this day, as well as in conversations during other meetings, was what is at stake for people with dementia when contemplating their diagnosis.

After Sharon asked the group about diagnosis, the group seemed to collectively pause in contemplation and perhaps, discomfort. Breaking the silence, Richard, a regular, long-standing member, explained:

'I think I went alone, to the GP, I knew something wasn't quite right...or probably Mary [his wife] came along, but we waited to tell the girls [his daughters]. I was worried about telling them the news [of his Alzheimer's diagnosis], and wanted to be able to answer their questions...Mary and I had to talk it through beforehand, what to tell the girls...but also about sorting our own things, so they wouldn't worry about things needing doing.'

Another member of the group asked him, 'And how did your daughters take it?'

He answered, 'Well, really - we'd talked about my going to see the GP before, so I

don't think it was a big surprise. I was worried Susan [his daughter] would cry, but she was alright...it was harder for Mary I think – to tell the girls – but we managed.'

A woman in her late sixties with early onset dementia described her experience,

'It was a while ago when I was telling my sister – she lives in America...we're twins! Anyway, we talk on the computer, with the camera, especially since she had cancer a few years ago, and our brother too, I use the computer to talk with him. But I called her, it must have been after the GP told me I had Alzheimer's, and I remember telling both of them [her brother and sister via Skype] that I had Alzheimer's. I was nervous before, I put it off for a while before Stuart [her husband] convinced me to go through with it. And you know what my brother says to me? [laughs] He says, 'Maggie, what's that? Old-timers? Well, don't we all have that? I can't remember my name half the time!' [laughs] ...Bless him, we laughed, my sister too and it made me feel better, that we chatted the same and they didn't seem to care, really.'

Other people in the group made comments such as 'Well, I don't really remember going to the GP' resembling Maggie's and Richard's accounts in that clear

memories of the day, setting, or moment when they received their official diagnosis were absent.

Additionally, many people's memories of 'all the appointments leading up to it are a bit foggy – they happen in the midst of everything else.' People seemed to shrug off the actual event. Those that did not speak directly about having been given their diagnosis, instead spoke about its relevance. Specific questions about the official event of the diagnosis often elicited responses that it 'wasn't so important' because 'it didn't make so much of a difference – it's not as though the diagnosis is what makes you have Alzheimer's', and, as explained by a particularly comedic member, 'Well, that's what's ironic isn't it? I can't remember it!' These comments illustrate that the event of confirmed diagnosis did not seem to hold a great deal of gravitas as an event in their lives. What emerges is that diagnosis often served to initiate contemplations about what they themselves would have to do in response. Instead of a clinical encounter in which a diagnosis was received, people instead remembered their worries preceding 'when I went to the GP' and about telling their diagnosis to family and friends.

My interlocutors' responses echo Kaufman's findings that 'historical' events, such as a war, did not significantly feature in her aged informants' biographical

narratives, and instead served as backdrops, or a 'point of reference in time, [but] not as an effective agent in their lives' (1986: 80). My informants with dementia worried about how their family members would 'take it' or what they would 'think'. The actual dementia diagnosis was the 'historical' backdrop of this more pressing concern and event of disclosure; 'to tell or not to tell' (Beard 2004: 423) was a pivotal plot point that could permanently change the course of their social and familial lives. Thus, the event of official diagnosis became almost a non-event in the lexicon of group meetings in comparison to my interlocutors' interpretation of the event of disclosure as marking a transition in their lives (Hareven 1978). Thus, diagnosis served as a shallow 'point of reference in time' or the past: one which was blurry and temporally ill-defined. Importantly, it did not offer insight into when dementia started, nor did it necessarily pinpoint when it began to affect people's social worlds.

What also emerges is that disclosure was not a temporally static event or a singular incident that resided neatly in the past. Instead, it was frequently revisited, in that people with dementia had to disclose their 'memory problems' more than once, and to various people. Many of my interlocutors with dementia told me that they decided to tell their children or siblings about their dementia, and only revealed their diagnosis to other relatives or family friends later 'if it seemed like



the right time'. Many discussions in support groups centred on worries that they might need to tell someone, most likely strangers, that they had 'memory problems' when they were out of the house needing to accomplish something or while asking for help in navigating buses or making their way around large supermarkets. They lamented when they had 'had to admit it' to a stranger or acquaintance.

For example, a woman explained to me in an interview that she had gone to the cinema with friends, but had forgotten they had decided to go to a later film time.

She had arrived at the cinema two hours early. She told me she then had

to find something to do until they came. I wasn't going to go home, so I did my shopping, and then when my friends came they asked me why I had my Tesco bags with me. And I, you know, just said that I was missing a few things but then I realised I had frozen things in the bags. You can't just let it sit in your bag for the whole film, so I covered it up with my jumper.

Another woman explained during a group session, 'I always make sure I've got everything – I'll check my purse at least twice for everything, before leaving. I've also got a mobile now too. I like to pack tissues as well, because you never know

when someone will need one, and it's nice to offer.' Other people in groups for people with dementia spoke about having decided to 'go out less' since their 'memory problems started' because they feared becoming lost or disorientated (discussed further in the next chapter). Occurrences that could transpire while someone was 'out' seemed risky because they might precipitate needing to ask for help in a way that would 'make someone think, oh, she has dementia'.

It should be noted that there were also a number of people with dementia who did not seem so bothered by asking for help from strangers, but all acknowledged that 'you don't have to say 'Oh please, help! I've Alzheimer's!'. Using Goffman's discussion of presentations of the self in everyday life (1959), the examples above illustrate that the moment of diagnosis, or rather *disclosure*, is an important event in one's ongoing process of image management. Narratives about moments of past disclosures demonstrate a careful attention to the 'performance' of memory issues and requests for help, as well as preparation for times when one can helpfully offer a tissue, so as to minimise the extent of their exposure as person who is seen as cognitively diminished (Beard 2004) or in need of the help of others. What is also clear is that a moment of disclosure and its negotiation do not stay rooted and tied to the past. It recurs, and its recurrence is a possibility that must be managed repeatedly.

*'Finally getting the diagnosis': an event without clarity for carers.*

Many carers referred to the event of diagnosis as having 'finally happened' after a long period of multiple GP appointments, false diagnoses, and interchanging periods between when 'things seemed to be alright' and when they suspected that 'something was wrong.' In a number of cases, these interludes of ambiguity lasted for years. Carer group members spoke in support groups about the frustration of 'actually getting it [a diagnosis for their family member]!' and a few would sometimes jokingly congratulate new carers on having procured a diagnosis for their person with dementia. Some carers spoke about their annoyance with '...the doctors who don't know what's what, really and then finally they give you the diagnosis and you think, OK, now let's start to get things sorted and then you realise – they can't offer you anything!' while others seemed resigned to the knowledge that '[n]ot much can be done really – so you just go home and it's much the same.'

During interviews, the drawn-out and ambiguous experience of arriving at a diagnosis was much more prominent. It was often this experience that carers first mentioned after I had begun an interview with my open-ended prompt, 'So, can

you tell me about your experience as a carer so far?'. In one such interview, a woman named Grace, who cared for her husband with dementia, described her experience to me:

'Well, we [she and her daughters] knew something had changed with Derek; he wasn't quite the same as when he had been working, but we thought – oh, maybe this is just him adjusting to being retired. But then, it lasted longer than we thought it should – him not really knowing what to do with himself really, and then other things – so then I says to him, why don't we ask the GP about it next time you go about your heart. And at first he got annoyed with me, didn't want to be asking him [the GP] about that, with his mood and such, so we didn't and he didn't get any better, really. So, then I made up another appointment for him, and told him we had to go again for something else, his leg was stiff I think, and then when he went off to the loo, I asked the doctor about things I was worried about. His mood mostly, but also him staying home most of the time and not doing anything complicated before that he'd do – he'd cook himself things when I was gone and usually had a puzzle going, or did the crossword in the paper, those things – and told him [the GP] that I was worried that something was wrong but that Derek

wouldn't hear it. So, the doctor listens to me, and says, well, you know, he might just be adjusting to being at home and I shouldn't worry. Maybe he's just a bit down because he doesn't have anything to do that's his anymore – his job and such. But he says he'll suggest to Derek to go out walking more, for his leg to keep the knee going, and give me time off at home. So, when Derek comes back he says all that. And I wasn't too happy about it, because I didn't think it would do much, but I wasn't going to start an argument, so I just kept my mouth shut and then my daughters got cross with me because I hadn't pushed – can't make anyone happy [laughs] – but well, of course it got worse. He got lost one time when he was out, and names started to come and go a bit. So finally, after another year, I went back to the GP with him, and then finally spoke to another GP. They did those tests, you know, the memory ones, with the penny? [Lilian: Like the MMSE test?] Right, yes, and well, then, we saw, OK, yes, he's having trouble and it wasn't just him not adjusting. And so finally, that new GP - I think it was the new one? - paid attention, and after some other things - other tests?, a scan, we were sat down and told it was dementia. That he thought it was mixed dementia. But that was a long time ago – five, six years ago? I can't really remember, but really, by that point, I mean we [she and her daughters] we knew it was

dementia; his mother had had it, so we had seen it all before. And then when I asked the doctor what to do next, he told me to get paperwork in order, for the money and medical decisions, and that I could get a disability parking pass for the car, but really, that was it. We'd have another appointment in a year, but he said there wasn't much they could do for the dementia really. The GP said it was mixed; I think I said, so not only Alzheimer's – and that's the only one they have medication for. Which I've heard the women in the [carer's support] group say.'

I then asked Grace, 'So you don't think the diagnosis was particularly useful?' She replied,

'It hasn't made that much of a difference, no. It took so much effort to get it – to know finally, OK, that's really what's going on, but things really went the same as before. It wasn't a big surprise for any of us, and he [Derek] was a bit depressed about it I think, but then I don't think he remembers it now – that's the good part! [laughs] – and he never really wanted to tell the children, asked me to do it, but mostly it's just helpful to get you onto things like the Alzheimer's [Society] groups, or with the council for the stipend.'

In Grace's winding narrative, which resembled many I was told in interviews, there are parallels with people with dementia's experience and memory of the diagnosis event. A diagnosis is something that is often consciously sought by carers and families, yet after it is given, it is rarely seen as particularly informative or momentous to their overall experience. When I asked carers why they worked so hard to get this diagnosis for their person with dementia, they often told me things such as, 'Well, I thought it would matter, I suppose. I thought it would solve something. But it hasn't really, has it? Just gave me the peace of mind I suppose, that I hadn't been making it [her husband with dementia's odd behaviour] up.' Grace's story shows that diagnosis lacks significance as an event in carers' narratives and does not register as particularly new information for carers, particularly as many of my interlocutors' doctors often made a diagnosis of specific subtypes with limited certainty. Diagnosis was instead a confirmation by doctors that what carers 'thought was happening' was indeed happening. It confirmed a sense of confidence in carers' own ability to 'see the signs'. In group conversations, GPs sometimes feature as 'experts' who '...don't really know what to look for really, do they?' The difficulty of convincing doctors to see 'what you're seeing every day' was clear in carers' frustrated tones, and some carers wondered that because '...it isn't something they can really fix, so maybe they're not as willing

[to diagnose the condition]?’ They compared their own actions to those of doctors, and often found that they themselves ‘...really knew what was happening – if he’d [father with dementia] kept going by himself the doctor would have kept sending him home with vitamins, I swear!’.

Carers also highlighted worries about telling their families, mostly centred on how their relative would feel about the event of disclosure. Grace’s agreement to tell her and husband’s children herself is illustrative of many carers’ desire to lessen the social impact and discomfort of a diagnosis. In line with this, others also explained that for a time after the diagnosis was made, there seemed to be ‘an agreement’ with their spouse that it was not to be mentioned or brought up unnecessarily, mirroring norms in support groups for people with dementia. Here we can see an attention to minimising ‘events of disclosure’ within intimate relationships as well. A number of carers mentioned that they and their spouse referred to dementia or the diagnosis so rarely that they were ‘not sure if maybe, maybe most of the time, he’s forgotten that he has it, or that we even went to the GP!’

Thus, in many carers’ narratives, short-lived relief was followed by continued uncertainty. Diagnosis did not seem to ‘really change anything’ and in retellings



of the past, seemed to be just another event in the overall environment of ambiguous experiences of caring for someone with dementia. Yet while carers' reflections on the event of a clinical diagnosis illustrate that it did not lend much clarity to the day-to-day management of their relative's condition, many mentioned that the diagnosis 'wasn't completely useless.' It was helpful in bureaucratic processes that came after a diagnosis was made, because it was 'official'. On a number of occasions, in 'trying to remember' a diagnosis several years back, carers explained that 'Yes, I think you actually have to have someone with a diagnosis to actually come to the groups – so, I didn't meet all the ladies till after then, four years ago, then?' This topic is discussed further in Chapter 4, but here I note that referrals to Alzheimer's Society services, stipends and disability accommodations, and the authority to initiate powers of attorney were made possible by 'that sheet of paper from the doctor.'

Despite 'helping to get the ball rolling, as they say' in 'official' arenas of their lives, a diagnosis blurred the temporal parameters of dementia as a feature in their lives more generally: 'It didn't change anything so much, so sometimes I have to remember when exactly he was diagnosed.' Carers often used the timing of when they began attending Alzheimer's Society services as a way to deduce the date of the diagnosis. For my interlocutors with and without dementia, the event of

diagnosis did not create any solid division of 'before' or 'after' dementia in the retrospective appraisal of their experiences. For carers and people with dementia alike, confirmation and disclosure of a dementia diagnosis is a socially embedded experience that unfolds over time. How this knowledge affects family and friends plays a paramount role. Repeated disclosures in the lives of people with dementia complicate and blur the divide between the past and the present, in much the same way as 'finally' getting a diagnosis blurs the borders of the past for carers.

Considering that diagnosis is an inaccurate or unhelpful place to 'start' the story of one's life as affected by dementia, what, then, is more useful? While diagnosis may not have counted as the 'beginning', it does nonetheless have major implications. In the next section, I argue that the relational histories of people's lives are at the centre of people's conceptualisation of when 'it all started.' No 'beginning' instigated a search for 'when it started' for carers, and disclosing the diagnosis had to be approached with care by people with dementia because their very agency might hang in the balance.

### **The Ramifications of Diagnosis**

### *An Afternoon with Pearl*

Pearl picked me up from the train station on a Thursday afternoon, waving to me as I dashed through cold Spring rain and into her car. I thanked her for the lift to her house and for doing an interview with me. She tutted at my appreciation with a quick, warm, 'of course, love!' and then began to tell me about her neighbourhood. Trees lined the residential roads we drove along, shielding rows of neat, modern-looking one-storey bungalows, with equally neat and geometric front gardens. Pearl told me that she wished she and her husband had '...raised our boys here, it's farther from the city, and there are other families – I think our youngest, especially, would have liked it, but where we lived was more central – no gardens. But the grandchildren come and play outside – when the weather's nicer than this! [laughs] – otherwise they muck around in the garage, so we're making use of it now.'

Sitting in Pearl's neat, cosily decorated living room, we spoke about her husband who had dementia and lived at home, her sons with whom she spoke often, and her grandchildren, whom she saw regularly. She told me,

'...I think it was hard for my husband in a small house, with three boys. They were always under his feet, and he shouted sometimes, and that was difficult for my middle one, Jim, him there.' She pointed to a framed picture of three men in their 40s squinting into direct sunlight, which overexposed the planes of their faces. 'He's more sensitive and he and his father...they had the most difficulty, and he's had the hardest time to now, coming to terms with it [his father's dementia], and so we talk about it the most, between us.'

Our conversation turned to the carers' group Pearl recently joined and which I had been attending for the past few months. Pearl explained that,

'I hadn't realised there was so much to learn [about dementia]! Shona [the AS group facilitator] and rest [of the group] are so good at explaining what it is exactly, what it does...that he has Vascular, which is different than Alzheimer's actually, and everyone else [the other group participants] know so much as well, even before they seemed to see the signs properly. You know, one of the woman, Spanish, I think – Marta? – Well, she said she thought something was off for a good while before going to the GP, because her father started coming home with all his

money spent – but he'd always been so frugal when they were growing up. I came home from group thinking...and when I talk to the boys, about when it could have started, really...'

Pearl's voice trailed off and she looked down into her empty cup of tea. I prompted, '...made you think differently? About your sons or Robert [her husband]?''

'I suppose, I wonder – because I was just talking with Jim last night actually – and we were talking about an argument he and his father had ages ago, really a difficult time, they didn't speak for almost a year after.'

'Can I ask what happened?' I probed.

Pearl drew in her breath, as though summoning stamina for the monologue to follow,

'The boys – my grandsons, Gavin's [her eldest son] and Jim's sons, were over here one afternoon, and playing or working on something in the garage and I was in the house...when I hear shouting and yelling. Lilian,

it was incredibly loud – and I run to the side of house, and there's Richard [Pearl's husband with dementia] yelling at Leo – Jim's son – with the two other boys, Gavin's sons, are off the side, and he's yelling at Leo, shouting 'What are you doing out here? What are you doing touching all my tools!' and going on, like 'They aren't yours! You go back home! Out of here!' and really, only at Leo, and poor thing, he was so upset, and I bring him into the house and he calls his father [Jim] to come pick him up. And Jim was so upset, so angry – shouts at his father, saying he's not to behave toward his son that way, and that he's terrible for playing favourites...and he barely came round for a year, and when he did it was really only to see me, but he would barely say anything to his father – just what was civil, really. But I was talking with Jim yesterday about it again, because of what we talked about the other night [in group] when Christy [another carer in the support group] said her mom was getting confused years and years ago, and I thought – maybe that argument was the dementia already. It was years before Robert really started forgetting and we went to the GP [Robert was diagnosed with vascular dementia two and a half years ago], but really, he wouldn't do something like that – Leo was so hurt – and I say it to Jim, maybe that was when it was starting, the dementia I mean, five or six years ago. But Jim just says

to me, 'Mum, that wasn't the dementia – that was Dad, he's always treated me different, and he just took it out on Leo, he was just mean...' and I tried to argue, but he didn't want to hear it, he just really thought his father was like that with him, and Leo...'

What we see in my interview with Pearl, is the way she re-examined past memories of her family's interactions to try and grasp 'when it [the dementia] really started'. Pearl referenced conversations in support groups, and how others in these groups suspected 'something was wrong' long before diagnosis. Listening to others' examinations of their past prompted her to reappraise her own memories of the past decade for similar signs that might point to 'when it really started.' This can be seen in the way Pearl considered new possibilities about the significance of her husband's past behaviour after listening to how Marta labelled particular types of behaviours exhibited by her father as indicative of dementia having 'already been there'. Many other carers spoke about their past this way in groups, and these extended re-examinations were often prompted by carers asking each other, 'When do you think it really started?' I suggest that the subtle instruction in narrativity that carers are given in support groups informs the way in which they engage with the past. In support groups, and conversations after group meetings,

carers treat the past as a reservoir of memories that contain clues and signs signalling when the 'story' of dementia in their family began.

*Carers' re-examination of the past: blurring notions of behaviour and 'when it all started'.*

In re-remembering memories of the past, and then re-examining those memories for 'signs' of dementia, particular memories and aspects of those memories emerge as potentially problematic. The following exchange between women attendees of a support group reveals the types of memories commonly shared:

Marcie: Well, I also thought that it [the dementia] started a year or so before he had his [her husband's] diagnosis, but I was talking to his sister last week, and she asked me if I remembered the time he went shopping by himself, for Christmas presents, and then came home with something for a baby, really simple, but all the grandchildren were in school by that point. And it made me think of what you had said, Claire – of Bruce stopping with the shopping – maybe it started earlier than I thought, really.



Claire: That's right, Bruce hasn't done the shopping in years. Will only go with me now, and before he was always set on going to butcher's himself. Looking back, I wonder if something happened while he was there [at the butcher's], made a mistake or got embarrassed so he quit going. He was always a bit sensitive.

During conversations like these, carers' re-considerations of their own pasts and memories that held possible import as a sign of 'dementia' were added to the 'trove' of carer groups' working knowledge. Indeed, both Pearl and Marcie mention other carers' experiences and re-examinations of these experiences to reassess their own person with dementia's past behaviour. This communal re-consideration of the past, and perpetual instigation to do so, illustrates that the memories which carers re-remembered in these conversations are often tied quite strictly to a desire to figure out 'when it all started'. This time-point is consistently reworked and up for debate - similar to a person with dementia's 'official' diagnosis and disclosure of that diagnosis. Further, we see that carers pay particular attention to when their family member with dementia began to 'act strangely', either because social interactions went awry, or habitual patterns broke down. Carers are acutely conscious of the nature of social interactions of which their person with dementia were a part, particularly those with close kin. This

underlines theorisations of dementia as a 'social illness' (Kaufman 2006), highlighting that its most painful challenges for family members often revolve around the upending of 'normal' family life. Carers conceptualised the 'start' of dementia as a disruption of cognitive function, *but also* as a disruption to their social and family life. In my interview with Pearl, her distress at remembering the event in which her husband yelled at his grandson Leo was clear, and it seemed to shift her understanding of this event as one that fits neatly with an historical tension between her husband and his son Jim (Leo's father), to one with new implications. Robert's inappropriate anger directed at one grandson, and not his other, was cast as a possible symptom upon which the start of his dementia progression could be mapped.

Carers' attention to socially based behaviours is noted in other research (Chappell and Penning 1996; Chenoweth and Spencer 1986) which found that '*behavioural changes* [which] refer to the diverse set of noncognitive symptoms (for example, depression, irritability, psychosis, wandering, agitation, aggression) that fall outside the formal diagnostic criteria for dementia (which emphasize cognitive symptoms and functional decline)...are cited by family caregivers as among the most challenging aspects of living with a person who has been diagnosed with dementia' (Mitteness et al. 2006: 44, emphasis original). While that research

focussed on carers' descriptions of their current challenges in providing care for a relative, my findings show that appraisal of behaviour also serves as re-evaluation of past behaviours. This touches on emerging trends more recently advertised on public platforms such as the Alzheimer's Society webpage publicising research 'Investigating the effect of Alzheimer's disease on social behaviour and anxiety' (Alzheimer's Society 2019). The webpage cites a caregiver member of the Alzheimer's Society Research Network, 'Dr Dachtler's investigation of the amygdala *provides remarkable confirmation of what we have all observed*. Behavioural change is indeed the earliest external marker of the onset of AD and intervention at this stage could well prove beneficial' (emphasis added, Alzheimer's Society 2019). It is clear that emerging biomedical attention to 'signs of onset' of dementia are following behind carers' own, long-standing attention to behaviour as a significant clue of dementia. However, my material shows that all behaviour is not equal in this regard: that which disrupts family life features more prominently as the 'earliest' sign. In looking over their pasts in this way, carers impart a quality of medicalisation to these re-examinations that pre-dates a medicalisation of behaviour that might now be emerging in biomedicine and which was not discussed in support groups at the time of my fieldwork. Among my interlocutors, 'what he was doing ages ago' as 'only' a behaviour became

blurred and was tentatively cast as a 'symptom', within their own understanding of dementia.

Carers' attempts to 'figure out when it started' and reconciliation to 'the fact that you can never really know if it was the dementia' problematises the idea of a 'beginning' to the past, or the existence of such a time that lies in the sequential period before 'now'. Their attempts resemble mythic storytelling, in which the origin of some characters, Dementia in this case, cannot be known and their very existence becomes the tool by which a story's events are mapped. In other words, working out when 'it' began is less about plotting a specific beginning on a timeline, and instead more of an exercise in reordering the sequences of events for the purposes of the story being told. Pearl's account of how she thought that her husband's past behaviour toward his grandson was a sign of dementia 'already being there' is indicative of this. Moreover, in then considering her discussion of this suspicion with her son, who vehemently disagreed, it is clear that family members tell the narrative of these events through varying interpretative lenses, often pinpointing the arrival of the 'character' of dementia differently. The onset of dementia does not begin ahistorically; relationships, as they are re-examined after a diagnosis is made, are affected by pre-existing relationships.

Beyond blurring the temporal 'start' of dementia, carers' labelling of behaviours as possible symptoms also obscured the boundary between the disease of dementia and the idiosyncratic self-ness, or personality, of the person who now is seen as certainly living with dementia. In carers' re-considerations of a person with dementia's decisions and reasons for doing odd things, people with dementia's choices risked being invalidated or written off as dementia. This echoes research on the legal and social treatment of people living with mental health issues in the UK, which finds that often they are at risk of being seen as unable to make decisions unaffected by pathology (Jobling 2019; Keene et al. 2019). The ambiguity between behaviour and a label of dementia symptoms highlights how the cognition of people with dementia mental illnesses is viewed, and echoes MacIntyre's point that "...when the ill...*are* presented in the pages of moral philosophy books, it is almost always exclusively as possible subject of benevolence by moral agents who are themselves presented as though they were continuously rational, healthy, and untroubled" (MacIntyre 1999:2). In these reappraisals we see that the past behaviours of a people with dementia, *possibly* affected by dementia, are looked at in contrast to the 'continuously rational' and 'healthy' minds and actions of those without dementia – or *who* the person with dementia would have been had the dementia not started, or interfered.

*Looking for the beginning: a search for the separation between person and dementia.*

It is also important to note that in these renderings of the past, people with dementia are the focus and protagonists of these stories and past reassessments. Carers speak most about their person with dementia's movements, actions, decisions, moods etc. in specific detail, often describing their actions as the main plot points in the family and dementia narrative. This casts the person with dementia as the 'protagonist' or main character of these stories. However, as carers delve more deeply into their re-analysis of things that their person with dementia *did* in the past, two characters seem to emerge in the storytelling. The *person with dementia* and their *dementia* become separate entities who were at odds with one another, and their internal struggle drives forward the plot of the dementia journey and its challenges in family life. The separation between these two is established by the ways in which carers relate of a great deal of information about who their person with dementia 'was before the dementia'. Carers described their personality, likes and dislikes, relationships with family and friends, hobbies, skills etc., once again highlighting a person's social character, habits, and relationships with others. In so doing, the individuality and particularity of a person with dementia was enploted and presented as a character who is in control

of the trajectory and narrative of their life, and whose decisions 'make sense' to their families and friends.

However, as what a person with dementia did and said began to make *less* sense, then their role as the protagonist in control of their lives became suspect, and the entity of 'dementia' is foregrounded. People are seen to be 'themselves' when they remain, consistently, themselves. The suspicion that 'he just wasn't himself' indicates that carers not only thought of their person with dementia as becoming less consistently like themselves than they previously were, but also that their character make-up was not *just* their personality: instead it was being affected by, or shared with, the entity of dementia. Carers' questioning 'Do you think that was the dementia?' when trying to understand the motivation behind a person with dementia's behaviour, as exemplified by Pearl's pondering of her husband's treatment of their grandson, marks dementia as the new protagonist making decisions on behalf of a person with dementia. Memories of the past that cause carers to wonder when a person with dementia was no longer 'quite themselves' are also tied to carers' re-examinations of their own actions. Carers reassess how they interacted with their person with dementia, and ask themselves if their own behaviour counted as an increase in care. In groups, people spoke about having had to start to 'look out for him', 'just took little things over, just bits at first' and

'Well, you know, you don't do things just for yourself. So, I don't think I noticed that he'd stopped helping out with the washing or that notes we kept at home for food shopping were going missing without much more milk in the fridge!' Carers looked for ways they might have 'picked up the slack' as also indicative that a shift had occurred in who their person with dementia had been 'before' dementia began to affect them. In carers' re-examination of their own histories of care, ideas of independence become entangled in carers' reassessments of a person with dementia's past. As carers' trust in their person with dementia's ability to do things independently waned, carers' questioning of an intact 'undemented' personhood increased and people with dementia were placed more securely in an 'after it started' time frame.

At first consideration, it might seem that carers' retellings of the past, in which they attempt to re-examine and make note of a person with dementia's dwindling independence and individuality, works to threaten the status of the personhood of a person with dementia. I suggest, however, that these re-examinations of the past counteracted notions that the person with dementia was becoming 'lost' or 'gone'. In retrospectively labelling odd behaviour such as strange social encounters, becoming disorientated, and forgetting names as being consistent with the disease of dementia, and not the person themselves, this behaviour



became less representative of 'who he really is' or 'how she actually feels'. Separating the characters of the 'person with dementia' and 'dementia' allowed the former to remain, to a degree, intact. Actions when someone with dementia 'wasn't themselves' were attributed to the opposing character of Dementia. Pearl, for instance, tried to convince her son that a separation between her husband and dementia could perhaps explain their past memory of Jim's father's bullying his grandson. This mimics, partially, the ways in which Day's sex workers used different names for different periods of their lives, to house the different activities and behaviour associated with each character they wished to 'edit out' of current biographical descriptions of themselves (Day 2008). While the contrasting identities of Day's interlocutors lived in exclusion to one another, the characters of person with dementia and Dementia instead often resided, often uncomfortably, side by side in carer's descriptions.

This distinction between the two characters was also apparent in the way my interlocutors with dementia described themselves and their actions, as noted in other research (Beard 2004). Often, they referred to their illness as 'the dementia', rarely using the possessive determiner 'my', particularly when they spoke about having difficulty making sense of '...things I had always been able to do!' This subtle use of language illustrates that, like carers, they preferred to establish a

distinction between themselves and dementia, and in a way that emphasised the distance between them. A woman who regularly attended one of the dementia support groups often made the comment, 'I just wish they could just cut off my head! Or better – give me a brain transplant! Then this whole thing would be solved – without my dementia making me mess up all the time, I could actually just get on with things as I always have!' Her commentary often made other members in the group uncomfortable, because a number of times her monologue would shift into comments about wanting to die, an ideation staff members attributed to the depression she had developed as her dementia progressed. However, when allusions to suicide were kept to a minimum, members in the group joined in with equal vigour, jokingly asking staff members and myself 'if they've come up with that yet? I mean you should know Lilian, going to Uni in Scotland – they've cloned a sheep – why can't they just clone us and put a healthy brain in our heads to get rid of this thing [the dementia]?' The tone of these commentaries was often light and humorous, thinly veiling a sharper edge to many group members' frustration with 'this thing', which they conceptualised as an externalised, parasitic entity.

These illustrations of dementia sat in contrast to the medicalised versions of dementia I heard described by members in these groups on rare occasions. They

described dementia as a degeneration of the brain, in which 'holes start to develop, I know that, the doctor said it [a brain of someone with dementia] was like Swiss cheese' and 'you just lose mass, it [the brain] just shrinks, less elasticity – like everything with age! [laughs].' In these accounts, the separation between 'the dementia' and themselves was less clear, and instead progression was cast as a subtle and indelible process that resided within them. What is important to note here is that these renderings concentrated on medicalised explanations of their condition, whereas those which externalised the disease were shared during conversations that revolved around the frustrating social situations and 'what I'm having trouble with.' Akin to carers' descriptions, my informants with dementia carefully deployed different conceptualisations of dementia to protect depictions of their self-hood and individuality as intact 'underneath the fog' of dementia. These kinds of care and awareness of the need to protect their status was also apparent in their approaches of diagnosis disclosure, explored below.

*'When did I lose my brain, exactly?': the dangers of diagnosis disclosure and normalising dependence*

I described earlier that the *event* of getting a diagnosis was relatively unimportant for my interlocutors for dementia, but that does not mean that a diagnosis is inert

knowledge with no effect on their lives. In group sessions and interviews alike, people with dementia warned that disclosure of their diagnosis status had to be done carefully. This is because it could undo 'everything I've done', highlighting the importance of one's status as person with a lifetime of accomplishments, and also posed a danger to 'how people treat you'. These discussions about disclosure build on previous discussions in this thesis which have highlighted the socially embedded nature of people's recollection of life's events. An examination of people's discussions about the ramifications of disclosure highlights the paramount importance of being an independent decision-maker with agency, so as to be seen as a productive, contributory member of social networks.

The trepidation people with dementia felt towards a possible shift in the way they were seen and the nature of their relationships, echoes MacIntyre's assertion that '[m]odern moral philosophy has understandably and rightly placed great emphasis upon individual autonomy, upon the capacity for making independent choices' (MacIntyre 1999:8). What emerged in people's discussions about how one had or should disclose their 'memory problems' or specific diagnosis demonstrates that many are keenly aware that a dementia diagnosis has the power to threaten their social status as an independent person capable of making sound decisions in line with a coherent, unique identity. Individual autonomy

permits people to *be allowed* to 'still do things' and also shows that enacting independence is tantamount to being a moral person. This is particularly consequential considering the conviction of my interlocutors, carers and people with dementia alike, that 'becoming a dependent' or 'being overly dependent' was a turn of events to actively avoid. Threats to one's independence are not just annoyances and frustrations, but morally repugnant.

People with dementia often expressed frustration with their family members' attention to their diagnosis after they had received it. Many explained that they had not been able to control who in their immediate family did and did not know about their diagnosis because, '...things go through the grapevine you know. I didn't say anything, but I know my wife told her sister and then, well. The cat's out of the bag.' They often chafed at this lack of control – 'It's my bloody business, you know!' – and their frustration seemed to surface most often when positioned at odds with a relative who decided post-diagnosis that 'now, suddenly I can't do this or that anymore' or were told that they 'shouldn't have been living on my own for the past few years'. One woman exclaimed, 'Oh, I could have smacked him – when did I lose my brain, exactly?' They described these attentions as border-line offensive, 'even if I know she's just telling people because she wants people to be understanding' or because 'she worries about me – kind, but unnecessary'. These

complaints suggest that carers' 'broadcasting' of, or reactions to perceived diminishment crossed certain ethical social lines for the people with dementia.

Some of my informants, most often those who were particularly careful about whom they disclosed their memory problems to, spoke about feeling under continual surveillance by kin who knew about their diagnosis. They spoke about being aware that relatives '...were watching me, I could tell she thought something was wrong, like she was testing me to see what I remembered. And of course, I forgot some things, but it's terrible being watched like that.' One woman explained feeling like '...he [her husband] was always predicting where I was going to go wrong. It made me so angry, like he was waiting for it.' Flora, a woman with whom I got on very well, explained to me that she was having to be 'careful' about telling her semi-estranged son about her dementia,

...because I think he wants my house. I spoke to Claudia [an Alzheimer's Society staff member] about it, and she said I was right to be careful. Sometimes after you get a diagnosis, family can come in and decide that you're not fit to be on your own, and shuffle you into a care home, and then once you're in there they *really* don't believe that you're fine by yourself. And remember, oh when? Some meeting ago, I can't

remember, when we were talking about being diagnosed, and she [Claudia] told us about how the GP should tell you right then, that you don't have to tell anyone? And then Margo said that about that, that she hadn't told anyone, no one, and I thought, oh, maybe that's the way to do it because you're also just not worried about why people are asking you the things they are.

These anecdotes illustrate that the social implications and dangers of disclosure was not just a passing concern, but legitimised as a primary one within the space of groups by its members and facilitators. Those living with dementia were keenly aware of the dangers which disclosure, or unskilful disclosure, posed to family relationships as well as people with dementia's legal hold on their own decision-making, a topic examined further in Chapter 4.

While I have illustrated people with dementia's exasperation with being treated or seen as dependent, I do not wish to give the impression that they were not aware of their need for help, or that they always chafed at being offered or receiving help from family and friends. Indeed, the dangers of disclosure are not so straightforward as to only warrant hiding it, particularly since my interlocutors' familial lives were varied and complex. Many, for example, spoke with pride about

how helpful their children had been 'since I've been getting confused', and with awareness that their spouses 'have had to take on a lot'. During biographical anecdotes, many spoke of the loving mothers they were raised by, and the supportive and caring social networks upon which they relied in the recent past and present. For instance, Ethel, one of the women in the inaugural support group presented earlier, told the group that 'really, my daughter is such a help – she drove me [to the meeting] today' and Fred corroborated this recognition of dependence, explaining that '...she [his daughter] looks after both of us [he and his wife], makes sure we're alright. At home my wife and I manage fine, but Beth [daughter] drops by often – a sweetheart, as they say where you're from!' [laughing, as he pointed at me]. Lucy went on to mention that she was worried '...that I'm getting in the way, really, my daughter and her partner both work so much, and they have two dogs...but they've had me move in with them, because I was finding it hard to live on my own, you get lonely. But sometimes I do worry that I'm in the way.'

I suggest that people with dementia's acknowledgements of how others have cared for them, and the help that they have appreciated and needed, did not conflict with the important moral project of being an autonomous and independent individual. Rather, this acknowledgement of one's need for help



corroborates one's independence. Being able to recognise the limits of one's own ability to 'be fine on my own' and to acknowledge their need for care, people with dementia showed that they possessed and exercised 'the virtues of the independent relationality' that not acknowledging dependency would threaten to 'obscure' (MacIntyre 2003: 9).

Interestingly, and perhaps unsurprisingly, many of my interlocutors with dementia were more comfortable with attributing this dependency to 'being old.' During a support group meeting conversation in which members spoke about 'the double-edged sword when someone helps', members described their alternating annoyance with and gratitude for their relatives' care. One man threw up his hands, saying 'Well, sure I need help – I'm old!' Nods followed around the room, and another woman said, 'Yes, right – it's almost as if they [family] wanted to decide everything for you because you're having trouble with your memory. But really, I have to ask, wouldn't they be helping me regardless [of dementia]? I would still need help with some things in the house and garden.' At this, one of the women in the group turned to me and asked, 'Do you have grandparents? Is she all on her own?' I confirmed that I have one living grandmother who lived alone in her own home 'just fine', but admitted that 'my dad goes around to hers at least a few times a week – she doesn't need a lot of help with everyday things, but he's

always fixing stuff in the house, and sometimes takes her to the doctors or things.’ The woman nodded quickly, saying ‘See?’. In conversations like this, the ambiguity of ageing and senility is revisited, normalising one’s need for help, *as well as* family members’ offer of help. In casting the reason for and target of help as ambiguous, my informants with dementia were careful to protect their status as social subjects who were independent and dependent in *the right degree*. Practices of disclosure and negotiations of help as one’s dementia progressed are entangled not only with notions of independence in successful ageing, but also with respect for the demands and expectations of family relationships.

*Mapping out a support network to preserve independence.*

While support groups are set up to be helpful by providing information, a common reason that carers and people with dementia come to support groups in the first place is linked to loneliness. Support groups are a chance for people to socialise with ‘someone else!’ beside their carer, or person with dementia. They seek out others ‘who understand’ the challenges of dementia, but also the tightly bounded nature of the relationship that can grow between carer and person with dementia. As will also be explored in later chapters, this relationship often leaves little room for the independence of carer or person with dementia.

As with Richard's arrival to his first carers' group described in the previous chapter, a new carers' arrival and description of having 'finally gotten a diagnosis' often prompted questions about that person's support network. Group members often pointed out that it was important to 'think about who might be able to shoulder some of the caregiving.' A seasoned carer in another group remarked,

You've been caring for a while now I imagine, but you've got the diagnosis now, so now you can figure out ways to get support. I know the GPs don't know much about what to do next, but learn from us – you have to get help. You can apply to the council for things, and now that you know its Alzheimer's you can tell family, and have them help.

While the event and lead-up to diagnosis may have been a period of ambiguity for carers, support group members unambiguously encouraged each other to 'figure out ways to take time off'. The event of diagnosis, often instigates a realisation of the need for respite. Respite was most often explained as necessary to create distance from the 'whole situation' of the caregiving context and their person with dementia, so that they might have a chance to 'do something that I want to do – for once!' and 'recharge.' Interestingly, in a number of instances as well, carers mentioned 'wanting to get out of the house to make sure that he *can*

still be on this own'. A few conversations underlined the danger of 'assuming' that a carer is needed all the time, and 'giving into the fear that something will go wrong if you're not there.' The importance of 'distance' was an undercurrent in carer support group discussions, which almost totally revolve around the details of a person with dementia's health. Such discussions are obliquely about the carer themselves: they learn to frame their past experiences before and after the dementia, and to share anecdotes about themselves and their activities in ways that focused on their person with dementia.

Distance between a carer and their person with dementia were not only sought by carers. People with dementia strategise their diagnosis disclosure in ways that avoid creating a dynamic of dependence in which they are always in need of help. Thus, carers' moves to expand their own independence allowed for a greater sense of independence on the part of the person with dementia as well. One 'recently freed' carer said that, 'it feels so wonderful [just] having days that are bit different between them...have a bit of space' between themselves and their loved one with dementia. Likewise, a few people with dementia made comments such as, 'I felt like my own person again – and for once, I didn't exactly know what he'd done all day either' after their family member who helped care for them 'got away'.

Corroborating this point, Thomas, a person with dementia, admitted a bit bashfully during a support group meeting that he likes to go to the community day care centre, and that 'it was one good thing to come out of the diagnosis'. He explained that he 'chooses to' because then he can 'be away from [his] wife, who gets frustrated with my questions, I think'. He explained that he thought 'she deserved some time off' but that, moreover, it offered him 'a sense of independence' because he can make decisions about his own care, and his own time. Tactics such as these were considered 'smart' and 'good' ways of negotiating the ongoing disclosure process that can happen with a spouse, in which someone might feel surveilled. Thomas's decisions echo others made by those living with dementia, in which they highlighted needing to 'make my own decisions', and spend time differently than their carer. Many of these conversations seemed to rest on challenging the notion that they have 'nothing new to tell anyone'. In this we can see the significance of continuing to tell new stories and anecdotes about one's life; a number of people feared 'just becoming one of those people that just sits at home all day – you know they have nothing to talk about because nothing ever happens.'

This mirrors carers' own desires for 'something new', and is a powerful way in which the personhood of a person with dementia can be seen as still intact by

mirroring, to some degree, the independence of the carer. In recognition of 'how much' their family members 'do' and wanting to support their family members' wellbeing, many people with dementia spoke about ways to support their 'freedom'. Michael explained that 'I can't be calling him [his son] all the time; he has so much on already and can't be coming round to mine to check on things all the time.' 'Trying to do as much as you can' and 'thinking about ways to lighten the load on your wife [or other 'main carer']', help out where you can' was often encouraged by other group members and staff members.

The fact that carers and people with dementia seek rest from their relationship with one another denotes how emotionally demanding it is. The ways in which they seek to maintain the balance in this relationship signals how important this connection is, and what is at stake if this connection were to be lost. Other implications of the tautness of this caring relationship, particularly the implications it has for how degrees of relatedness are conceptualised between family members, are explored in greater detail in following chapters. Here, the pertinent point is that mapping out support networks to sustain carers and help people with dementia, is a function of people's disclosure of 'what is really going on', in terms of a person's official diagnosis, but also the emotional, relational, and physical 'reality' of living with and caring for dementia.

## Conclusion

What emerges in this chapter is the complicated relationship people with dementia and carers have with their pasts, a diagnosis of dementia, and indeed the disease of dementia itself. In all these cases, the 'facts' of the matter are ambiguous, constructed, and contested.

As I have shown, there is no real start to my informants' experiences of 'dementia.' For carers and people with dementia, the event of diagnosis was either a confirmation of what was expected or already suspected, or did not feature as meaningful memory. The changes to their lives that 'got [them] to where I am now' and brought them to these support groups never truly 'began' and is never truly settled on: 'You can never really know when it started, can you?' Instead my interlocutors' lives *with dementia* emerged, slowly, and often through a haze of uncertainty. This might, on the surface, seem to coincide with common biomedical understandings of dementia as a progressive illness in which cognitive degeneration accumulates over time. However, this would belie the relational significance of the events that my informants identified as lending clarity to the presence of dementia in their lives. Indeed, people with dementia felt the impact

of dementia most acutely in comparisons of biographical narratives highlighting their lifetimes of responsibility, accomplishment and support of others with those about being treated as dependants or 'a bit doolalee' in the present or recent past by family. My informants with dementia were keenly aware of the everyday consequences of disclosure that 'made it a bigger deal than it is.' I also showed that carers reassessed the past to determine when dementia began by searching for when their loved one 'acted differently' toward family and friends, marking social behaviour shifts as signs of dementia. In so doing, they separated out the effects of dementia from the choices and actions made by their person with dementia, akin to the ways that dementia support group members localised dementia to 'bits' in their brain that could be removed. This contributes to conceptualisations of dementia as an 'overlay' to 'who' their person with dementia was, as opposed to a disease that fundamentally changes the person 'underneath' the disease. Who a person with dementia is – his or her 'there-ness' – was tentatively and hopefully redrawn and protected from accounts of dementia as a progressive illness that subsumes the person diagnosed. Thus, the material in the chapter gives insight into the socially embedded nature of illness of dementia, and identity within the context of dementia. I showed that dementia is not only a 'social illness' which affects family members beyond the person diagnosed (Kaufman 1986), but that social relationships bring clarity to the dimensions of



dementia as a disease, the parameters of its presence in people's everyday experience, and its effect on the continuity of *the person* in dementia.

These often uncomfortable moments of 'clarity in which the presence of dementia in people's lives were brought to the fore were rarely singular or ever 'finished'. Without a past against which to stack experiences of present and future, commonplace ordering of events breaks down. Consider the ways in which support group members with dementia worries about unexpected disclosure moments, and strategies about when or who among close family, friends, and members of the public 'to tell or not to tell' (Beard 2004). Similarly, we can see in carers' re-examinations of the past that this work was never truly put to rest – instead, 'when it actually started' is often a hobbyist side conversation revisited whenever a carer 'just remembered something I'd forgotten happened'! What becomes clear is that due to the fluctuating nature by which people's relationships inform understandings of disease onset and disclosure, narratives and accounts of the past are slippery- do not, and cannot, feature fixed time points of 'beginning'. Further, accounts of the past are not universally held – those living with dementia disagree with carers, and family members disagree amongst themselves. Here then we see that the past is a narrative construction continuously reworked, and up for debate. It also a device through which people

mark out their identities, and report on their efforts to age 'successfully' (Buch 2013, 2015; Clancy et al. 2015; Lamb 2014).

Finally, this chapter has also sought to demonstrate the importance of independence and dependence established through being an agentive person with responsibilities in people's reappraisals and narrations of the past. Ideas held by carers and people with dementia about their independence are measured by the ability to 'act their part', 'decide for themselves' or 'do what they want'. I showed that carers and people with dementia seek distance and rest from their relationship with one another to safeguard their own, and each other's independence and autonomy, so that they themselves can retain an element of their autonomy, or at the best least pursue independent activities 'at least sometimes'. This is cast as an act of care; an acknowledgement of the need for care and reality of dependence following diagnosis, and also called attention to the importance of building support networks. Help, like disclosure, must be managed carefully, so that it does not topple the balance of power and attention within relationships that my informants carefully attend to.

What was not discussed in this chapter, but arguably belongs to the realm of the past, are those moments of temporal disorientation in which people with

dementia seem to relive past memories in present moments of their lives. This is one of the hallmarks of dementia, and caused a great deal of agitation and challenges for people with dementia and carers alike. In the following chapters, I discuss how people cope with temporal confusion that asserts itself in the *present*, even if that confusion may in fact 'resurrect' the past.



## **CHAPTER 3: Lost and Found in Time and Space: Problems in and of the Present**

In this chapter, I explore the most prevalent and pressing challenges raised by my interlocutors in response to questions oft heard in support groups, such as, 'What's been happening?' or 'Why don't you give us an update?' I found that the overtone of these concerns had to do with people with dementia's lapses into temporal and spatial disorientation to their surroundings. I take temporal orientation to mean the ability to understand time, stay in the present, and not become lost in memories or hallucinations of the past. Spatial orientation is the ability to know where one is, recognise locations, and safely navigate a course from point A to B. I examine the ways in which problems of disorientation are cast as 'problems of dementia' and significantly, how the time and place of a person's

actions or behaviour become implicated in judgements about whether a person was 'off', 'not altogether there', 'gone' or 'lost.' Munn claims that '[i]n a lived world, spatial and temporal dimensions cannot be disentangled, and the two commingle in various ways' (1992: 94), and similarly I do not approach the problems my informants raised as having to do with either a person with dementia's spatial *or* temporal disorientation. Instead, temporal and spatial disorientations often overlapped and were described as difficulty with staying orientated to, and in, the 'here and now'. The concerns and the strategies put in place by interlocutors to address problematic disorientation *to* time and space, and *in* time and space are the foci of this chapter. Strategies often involved careful attention to how they might alter power dynamics and a sense of relatedness between kin, and aimed to support people's autonomy and independence.

To capture the significance of people's movement as an overlap of time and space, in that people move *across space, over a period time*, I have included two visual diagrams. These serve to illustrate my interlocutors' 'disorientated' movements and carers' 'reorientation' paths, and shrinking, seasonal geographical ranges. In particular, I wish to draw out spaces within the home that become charged as areas important to relational and biographical histories, and how people sought to have people with dementia move through the home in

particular ways to become re-orientated to those histories. The diagrams build on information from interviews with people with dementia which showed that the 'essence' of their neighbourhoods was grounded in 'a sense of attachment and offers the potential for freedom of movement' (Odzakovic et al. 2018: 2). I focus one of my diagrams on the *inside* of the home, to capture the significance of movements there, and to blur the distinction between walking and 'pacing'. Further, my attention to my informants' attitudes to others' movements are informed by Munn's concept 'spacetime', defined as 'a symbolic nexus of relations produced out of interactions between bodily actors and terrestrial spaces' (1996: 449) from her work with Australian Aborigine people. Munn focussed on how people's movements that avoided particular areas created 'excluded spaces' out of respect for the spiritual or relational significance of these spaces. My work illustrates that people's 'disorientated' movements become those which carers work to 'exclude' from their relative's pattern because they are seen as relationally and historically vacuous, 'eerie', or 'non-sense.'

I divide this chapter into two parts. The first is concerned with people's activities within the home and the second with people's navigation of spaces in the outside world. This layout is informed by the division between these spaces that emerged in my interlocutors' discussions about disorientations and their consequences.

In part one, I illustrate incidents in which people with dementia became disorientated to shared routines in the home and did not recognise their homes. I unpack how these incidents were considered problematic, often resulted in added work for carers, and seen to threaten kinship ties by contributing to a sense of waning relatedness (Caldas and Berterö 2012; Orona 1990; Gjødsbøl and Svendsen 2018). This is juxtaposed against common associations of the home, in Western contexts, as the domain of women, and thus associated with nurturing, maternal, intimate and self-sacrificing care (Coston and Kimmel 2013; Gilligan 1982; Ungerson 2000). Indeed, it is noteworthy that the majority of carers figuring out care strategies were women caring for men. Further, it has been shown that in Western marriages, men commonly receive more social support than they give their wives, which can lead to men's lack of participation in social activities outside the home and declines in cognitive skills and processes (Lee and Waite 2018; Salthouse 2016). I thus contribute to larger, cross-cultural discourse exploring the house as an important site within which kinship is made and the house *as* kinship (Carsten 2004; Bloch 1993), and the 'unique importance of the home as the proximal context of late life living environments' in Western settings (2018:166). Homes are an important site where people 'do things together' at particular times and in ways that are constitutive of relatedness, underscoring other work



researching older people and social connection (Hazan 1984; Plath 1980; Taylor 2008, 2017; Orona 1990).

Not all routines are created equal however, and part one demonstrates that strategies crafted by carers and people with dementia tended to focus on those that fostered a sense of '*being with*' one another and connection (Berterö 1999; Caldas and Berterö 2012) that reinforced historical patterns of 'what I've- we've, always done'. This underlines the cross-cultural position of houses as a 'memory palace' and 'theatre of memories' in which the house serves as 'a structure for remembering' (Fox 1993: 23; Rosaldo 1980). Indeed, my interlocutors use their homes as *therapeutic tools* in order to re-orient people who have become disoriented to their identity, their surroundings, and the people within them. This speaks to research showing the home environment as a significant factor supporting or undermining elderly individuals' functioning in Western contexts (Iwarsson 2004; Rubenstein 1999, Stark 2001). As such, my material offers evidence of practical and conscientious uses of homes' 'capacity to act on those who live in them, even as they are made and erased by their inhabitants' (Carsten 2018: 114), beyond more symbolic interpretations.

Part two focusses on 'the outside'. I explore how fears of 'wandering', or people with dementia leaving their home at night or getting lost when away from their home, and coloured depictions of the outside and strangers as dangerous. I illustrate how the people with whom I worked, in turn, sought strategies to keep people with dementia close to home or monitor, limit and safeguard their movements outside of the home. This links to associations of people's 'wandering' away from the home, as a movement away from the safety of place of kinship, the home, where they can be 'properly looked after.' The impact of ageism, hazards, and limited mobility have also been identified as contributing to less frequent venture outdoors, and hindered social integration has been shown across cross-cultural contexts (Benbow and Kingston 2017; Smith et al. 2016; Vitman et al. 2013) and perhaps are most typified in UK campaigns to make communities dementia-friendly (Goodman 2018; Turner and Cannon 2018). Much research from Western-based dementia researchers on 'wandering' focusses on how to mitigate it and 'find' lost elders (Cipriani et al. 2014; Lai and Arthur 2003; Neville et al. 2006). However, others critique the very term as stigmatised (Halak et al. 2012) because it assumes that 'wandering' is a meaningless activity and a pathologized form of 'walking' (Brittain et al. 2017; Dewey 2006), which is generally encouraged as a cognitively protective activity for older people (Abbott et al. 2004; Barnes et al. 2007). These critiques demonstrate an ambivalence

around casting wandering as a straightforward 'symptom' of dementia (which is often based on the perceptions of carers and clinicians), which I also share.

Part two also shows that despite the dangers and significant challenges 'going out' posed, it was nonetheless considered 'good'. My interlocutors' conceptualisations corroborate other work describing 'the important role played by the outdoor environment as a venue for social activities among older adults' (Noon and Ayalon 2018:1) and the mitigating effect on depression offered by social cohesion in an elderly person's community (Choi et al. 2015). Drawing on Buch's work in Chicago with elderly people, I too examine the importance of boundaries between home the 'outside' in establishing 'social personhood' (2010, 2013, 2015: 40), showing its significance in mitigating the social isolation and claustrophobia my interlocutors felt as they became increasingly tied to the home and their relationship with one another. This chapter shows that efforts to 'age in place', and 'still get out' are negotiated alongside the ambiguities of 'wandering', and the 'danger' of the outside, as well as gendered notions about the appropriateness of people's whereabouts and their control over their movements. These factors present particular challenges to the relationships between carers and people with dementia, as well as their efforts to 'figure out what to do.'

## Part One: 'Timing it Right' and 'Remembering Home'

### *'It's a strange one': Tales of disorientation in a carer support group*

In a carer support group on a wet winter evening, an exasperated carer, Rose, spoke about the recent events of her life after Miranda, the Alzheimer's Society staff member leading the group, suggested they 'go around the circle and share how the past month's been'. Throwing up her hands in exasperation, Rose told everyone in the room, in her characteristic hurried Northern Irish lilt, that her brother, Derek,

had said that he would come over and take care of Mum [with Alzheimer's] for the morning because I had an appointment with the GP that I had already rescheduled twice because of things coming up with Mum, and I just couldn't again...I've figured out a schedule for feeding Mum to make sure that she doesn't forget to eat – which she'll do – and so she doesn't get upset or dizzy from being hungry. She has to have her porridge at 8:15 in the morning because then she'll know it's morning and she'll do the washing up afterwards. And then she'll also be hungry in time for lunch a few hours later when I come back from morning errands – I make it for her and we sit

together. And I tell this all to my brother – twice! – before he comes over last week and when I get home from the GP about 12:00, I ask her if she'd had breakfast and if the porridge was alright and she says to me that she didn't have any! And I ask my brother and finally put together that he didn't give her breakfast till after 10:00! And of course, she's confused about whether she's eaten or not, and not hungry for lunch I was ready to make and argued with me that it wasn't time yet, she 'wasn't hungry', she said.

Other carers around the group nodded along sympathetically, and attention moved to the person sitting on Rose's right. An older woman in her 70s named Julia spoke next,

What's going on now? Well. He's [her husband with dementia] become more irritable lately, I think the dementia has been getting worse over the past few weeks – but it's been coming on for a while...he'll get angry with me when I'm doing things around the house, and the past few weeks when Jana [her cleaner] came round...was hoovering and...and he starts shouting 'What's that? What's that noise?' and I'll have to have her turn it off and tell him again, 'You know she comes

'round and hoovers on Wednesdays.' It's becoming difficult; he's not wanting to do things he used to...was fine on his own before – reading in the study. Or we always read the papers in the morning over breakfast...retired years ago, but he still kept up with the business section or whatnot, in the mornings. But now he just goes around the house, pacing, not knowing what to do with himself, always underfoot. And then coming to me all the time to ask what time it is, or when we'll do things we've already done! I'm trying not to get cross with him, you know, and snap, but sometimes it's difficult.'

During Julia's update to the group, others nodded along, and she ended with, 'Well, you know how it is!' before clapping her hands down onto her thighs.

After a pause of 20 seconds or so, Maria, a woman who took care of her husband said:

I came home with him the other day from the Day Care Centre – you know that he's finally started going to – we drove back, before tea. And I come up to the front of the house with the car, park it right out front and he refuses to get out. Just refuses. And then he turns his head and

almost shouts at me – ‘Take me home!’ and he’s so angry. So, I tell him, ‘But Peter we are home, look behind you!’ and he looks again but then just looks straight ahead, and says, ‘That’s not my house, and don’t you think for a minute I’m falling for it and am going to go in there with you.’ I didn’t know what to do, really, it was like he didn’t recognise me. I tried to reason with him, but he was going in a loop and it was no use. So, then I drove around the neighbourhood again slowly and tried to, almost, narrate where we were going, ‘Oh, there’s Elmswood, almost home’, things like that. When we got back to the front of the house, I was able to convince him to go inside. God, it was exhausting – he almost did it again the other day, so now I’m trying to remember to name the streets as we drive home; I just hope this isn’t a new phase.

Maria finished without fanfare, only a small shrug. Two other carers spoke next, a pair of brothers who had recently joined the group. The first highlighted their troubles ‘getting mom to think about a care home – she can’t be left on her own, but she won’t hear it’, and the other spoke about ‘how strange mom acted sometimes’ and his worries that

she can't keep up with it all – sometimes when I come 'round, she even smells, like she's not doing all the washing. So, like he [his brother] says, we're thinking maybe she's got to consider help at least, if she'll even allow anyone in. She can be downright mean sometimes, these days.

The man to their right spoke next. John was a stout man who had 'a bit of a temper' but was also quick to laughter. He explained:

It's a strange one – a bit like what Jules was saying. Maybe you too, Maria. She [his wife] paces too, like you said, just going 'round and 'round the house but mostly at night. I think it's called 'wandering' or 'sun downing' when it's at night. And recently she's been quite agitated, going around the house looking in all the rooms, room to room...like clockwork as it gets dark. I can hear her going upstairs, shuffling...annoying, so I go up and ask her what she's on about, and she asks me where the children are. Almost panicked, she says she can't find them and that it's time for tea, that they need a bath. I didn't know what to say, really – bizarre. Unsettling, if I'm honest. We're in our 70s – the children moved out ages ago, we made up my daughter's room



into an office. But I'm not sure if I'm meant to tell her that – you know how the books say not to argue with them when they're like that? So, I bring her downstairs and say, 'Let's go look at the children' and then I show her all the pictures – of the grandchildren too – and...and I think that brought her around....then we had our tea and she seemed settled. But so strange – I know it's what happens, heard it from others, but to see her...room to room, just strange.

The strange and incomprehensible behaviours, as framed by carers above, centred on two themes: a person with dementia's problematic forgetting and disruption of household routines, as well as their trouble recognising their home as it currently was. Changes to household routines or an inability to recognise the home were emotionally distressing for carers and people with dementia alike – beyond mere inconvenience. Agitation, confusion, frustration and sadness were commonly cited, as well as worries that these behaviours were signs that 'things are changing now' and 'he's really going'. Thus, in this section I explore how people with dementia's falling 'out of sync' with the rhythm of home activities and memories of home complicated family relationships, contributing to anthropological framings of the home as an important site of kin-making (Carsten 2004), and as such, 'must be 'peopled'' (Carsten 2018: 103). Allerton's work in

Indonesia suggests that '[l]iveliness is central to the everyday significance of the house' (2013: 54), and that my interlocutors sought to maintain 'the right kind' of liveliness within their homes. I show that these disorientation behaviours and the distress they caused instigated strategies that worked to bring them back into alignment with the flow of familial life. In these strategies, the overlaps between time and space and temporal and spatial disorientation emerge, and these distinctions appear less important than their relational consequences.

#### *Orienting people to the temporal rhythms of family life*

In an effort to keep their person with dementia attuned to the patterns of family life, carers sought ways to help people with dementia remember the current time, as well as the social meaning of time. This is because carers and people with dementia placed value on doing the right things at the right time, recalling Bourdieu's emphasis on *kairos*, 'the right way and right moment' in constructions of habitus (1977: 20). Indeed, what was considered 'right' by my interlocutors was often determined by 'the way we've always done things' at home. Thus, knowing and recognising the home was tantamount to understanding the appropriate timing, details and rhythms of activities, in the space where 'the rules of social life are encoded' (Carsten 2004: 31).

On a few occasions, carers directly named hallmark symptoms of dementia, 'temporal disorientation' and 'spatial disorientation', when speaking about the challenges described in their updates, above. In educational sessions of the Alzheimer's Society, carers were taught that these types of disorientation were linked with people with dementia's difficulties telling the time and remembering the sequential order of 'how to do things – like make a cup of tea, or get dressed'. Session leaders described that these symptoms also disturbed people with dementia's visual and spatial perception, making it difficult to remember the layout of the house, and 'make a rug look like a bottomless pit' and 'a door across the room seem half a mile away'. Some carers spoke about the usefulness of large, obvious clocks, wall calendars and systems in which 'we write it all down, so I can remind her to 'Go look at the calendar!' when she has a question' as solutions to persistent questions relating to time. These tools were cited as helpful in support groups for people with dementia as well, and one man in particular showed how he kept 'everything on my phone – I can set reminders and alarms and see all my appointments!' Twice I heard carers speak about rearranging furniture to modify spaces that might be visually confusing. Although a few carers framed these disorientations as cognitive disruptions to a person's ability to process temporal and spatial information, these tools were posited more on their person's difficulty

in remembering how to find temporal information, and 'to make sure she doesn't trip over things', in recognition of persistent concerns about the significant injuries that could result from falling.

Beyond orientating people to abstract information about time, carers were far more concerned with orientating their person with dementia to the salient social significance of certain times and spaces of the home. The frustration of a breakdown of an orientation to 'what normally happens, when', is laid bare in Julia's palpable frustration and worry at her husband's disruption to Jana's regular routine, or her husband 'not knowing what to do with himself' at home and constant need for guidance. Carers did not only want their relative with dementia to know what day or time it was, but also what a certain day or time *meant*, namely, what they and others, should be doing and when. Equally important were people with dementia recognising their home and inhabiting the 'present' of their home. Indeed, later in this session John and Maria agreed that their spouses were 'lost in some memory' to explain John's wife's disorientation to her present life as a woman with grown children, and Maria's husband's 'forgetting that we moved here 10 years ago'. Here, the overlap between time and space is evident. Time determined the sequence of activities of the home, and the space of the home

represented a social history of one's own belonging to this space, and relationships to others who (had) lived there.

Interestingly, carers tended to people with dementia's bodies in particular ways to temporally and spatially re-orient them. To illustrate this, I examine the update of Rose, who spoke first in the support group session described earlier. Rose carefully timed her mother's breakfast of porridge for 8:15am to a few different ends. Firstly, as she told me in interview, 'It helped her [mother] understand that it was the start of the day. She always has porridge...it helps clue her in.' Secondly, timing breakfast for 8:15am prepared her mother's body to be 'hungry again at noon – lunchtime, when I get home'. Rose explained that when her mother was hungry, 'She'll know that it's time to eat, and will sit down at the table. I know that sounds daft, but for a while, her moods were bad...she'd get hungry but not put two and two together...' Rose's detailed breakfast routine aligned her mother's body's biological rhythms of hunger to specific time points, but, importantly, also to socially significant activities. Rose wasn't only concerned with her mother being hungry at noon, but at *lunchtime*.

Other carers discussed similar situations and strategies. During one group session, a woman named Carol explained that she had an evening routine with her

husband 'so that things go smoothly'. Every evening at around 4pm, she told her husband

that it's time for tea in a bit but first we should go for our walk – we'd always gone for walks in the evening during the summer around the park. And by the time we're back in from the cold you want some tea. And almost every evening, when we're back home, while he's gone to look for the biscuits and cheese, he'll usually say 'Oh, we've earned it.'

Carol's story echoes Rose's in that she also, subtly, organised the timing of her and her husband's routines to play up and play off those of his body. In these finely-tuned schedules that aimed to make her mother's body hungry at certain times, Rose attempted to bring both her and her mother's bodies in sync with *one another*. I suggest that carers were concerned with crafting routines in the face of dementia so that they could do particular, socially meaningful activities together – at the same time and in the same space. In this, an underlying ethos of '*being with*' at the heart of these approaches (Caldas and Berterö 2012) emerges, in which carers not only sought to strategically manipulate time (recalling Bourdieu

1977) but sought ways to take into account their person's experiences, and craft an 'understanding of their being in the world' (Caldas and Berterö 2012: 245).

The importance of the home life rhythms and routines also featured in conversations in support groups for people living with dementia who often emphasised the importance of control over who crossed over the boundaries of their homes. They warned one another to be suspicious of people they did not recognise who referenced 'appointments to cut the trees, or look at the roof' which they did not remember, and they often expressed wariness at strangers 'coming round'. Family members who suggested, or 'just decided' on changes that altered their routines, often by bringing in outside help were also often complained about. For example, Tabitha, a woman living with mild Alzheimer's, described her frustration with her son because

He doesn't want me doing all the tidying up anymore, at home. He's afraid it's too much for me. So they've [her son and daughter] started paying a cleaner to come in once a week, and she changes her time every week. It's frustrating because I can't plan for it really, and she goes through my daughter, so I have to speak to my daughter to confirm.

Here, the disruption caused by an unanticipated guest or service person was painted as threatening, and people with dementia acutely felt the danger such intrusions posed to their ability to decide on the running of their home, and being seen as 'able to manage'. My interlocutors' views underscore research with elderly Chicagoans that showed that they too carefully decided who may or may not cross the boundaries of their home (Buch 2015). While Buch's informants were not people with dementia or familial carers, and instead elderly adults who were contending with the implications of visits from home care staff, our material both shows that guarding the boundaries of one's home is a conscious strategy. It is a way by which older people safeguard their 'social personhood' (2015: 40) by negotiating the tenor of, and balance of power in, their relationships with others and maintain their independence.

As the home became established as the epicentre of my interlocutors' lives, carers often discussed ways to keep their person with dementia occupied while at home. These methods often made use of its materiality. Carers suggested finding tasks 'that she can still do...my mother-in-law, she loves to fold the laundry, so when she's over at ours – I feel almost guilty about this! But I save the laundry so we



can fold it together.' Lawrence, a man who cared for his mother, described his technique with a mildly embarrassed chuckle

I put out all the silverware and cups from the drawers and ask her to help me put them away 'after I've washed up' – she knows where they all go – mostly. And so it gives her a chance to feel like she's helping, and gives me about twenty minutes to get something done.

Another carer spoke about asking

him [her husband with dementia] to check the doors and windows at night, checked they're locked, so he'll go around the house and check them all – sometimes he'll forget what he's doing, bless, but then I'll shout 'Are the doors all locked for bed?' to jog his memory before he starts wandering. And I think the bonus is that he'll be less likely to want to leave the house then because he'll know – *time for bed and to stay inside.*

In these examples, we see carers using established home-based habituses to preempt the disorientation people with dementia might fall into, and allow them to spend time together *and apart* in productive ways. While these are not a sum total of all the 'little tips' shared in groups, they are representative of the ways in which many were subtly gendered. My interlocutors devised tasks that would allow people 'to feel helpful' in ways that fit gendered norm of occupation. Women were most often kept occupied with household tasks within the home, and strategies for men often centred on protecting or crossing the borders of the home.

People with dementia also spoke about what they did at home to keep themselves occupied. Cleaning, making phone calls, watching the neighbourhood, preparing meals, watching television, listening to music, reading books and magazines were commonly cited activities. Interestingly, many of these activities centred on leisure, and were, by-and-large, solitary. People often highlighted how these pursuits fell in line with what they had always enjoyed, in contrast to research approaches which focus on people with dementia's relationships and 'joining in' with others. George, a self-described 'movie-buff', had a reputation of being 'tech-savvy' and watched films on YouTube: 'particularly older films have been put up, officially or unofficially, I don't know, but they are feature length. Fantastic.'

Other people with dementia usually named their favourite genre of reading, television programme, or what they cooked and ate. This echoes the previous chapters' discussion of people with dementia's emphasis on establishing their identity through biography, and I suggest that in marking themselves as having unique routines and preferences within the home, they draw further on their historical embeddedness in the home to position themselves as independent subjects. Less often, but no less emphatically, many suggested spending time with friends or family because 'if children are around, then time goes by faster' and 'it's important to keep up with everyone'. Routines that included calling friends and family or watching the neighbourhood were also ways they sought to stay relationally connected to others even while being at home, demonstrating that place does not only indicate a geographical location, but also a positioning within a wider community.

*Home is Where the Hearth is: The home as a tool to trigger memories of relationality*

My interlocutors' experiences show that connection and relatedness between family members and friends can be threatened when home-based routines breakdown. I now draw attention to how my interlocutors used the materiality of

their homes and its socially meaningful spaces to maintain a sense of relatedness between people with dementia and their family members and carers.

By 'timing it right', Rose wanted her mother to be amenable to eating 'at the right time' so that she could 'have lunch with Mum at the kitchen table, which we'd been doing for ages' because when this strategy worked, '...some days it's like it was before the dementia'. Perhaps unsurprisingly, my interlocutors' activities and strategies to 'be with' (Caldas and Berterö 2012) one another described thus far centre on the hearth of the home, a noted, cross-cultural epicentre of relational activity and kinship-making. Rose's narrative eloquently underlines the relational significance of routines revolving around sharing meals, as well as the importance that eating has as an activity *within* the home. Rose times her and her mother's day around sharing a meal together in the 'breakfast room'. Similarly, Carol and her husband's evening walk is finished by arriving back home to share a treat, and Julia mentions missing reading the paper with her husband over coffee. This is reminiscent of Brijnath's work with Indian families caring for a person with dementia, in which tea and food prepared and ingested within the home was 'a way of making memory and building social relations' (2015: 118). I suggest that these anecdotes demonstrate that the hearth is indeed a site that exists in space, but also requires specific temporal rhythms to be truly socially meaningful. When

it was not possible for meal practices to adhere to their historical temporal and spatial patterns, people's desire to *share meals* together nevertheless was the most significant. For example, although Rose's brother Derek 'ruined' her plans, she postponed her own lunch in order to be able to eat with her mother later. Other carers spoke about eating 'something ridiculous, because that's what he wanted [for dinner]' so as not to start an argument and threaten the chance to 'have dinner together.' Brijnath also showed that food was shared between couples in ways and at times that diverged from what was normal, such as having ice-cream in bed at midnight, but that these moments nonetheless created a 'time for romance' (2015: 183). Here, the overlapping temporal and spatial qualities of 'the hearth' as a site to 'be together' emerge, but the meaningfulness of the hearth is more than a place within the home. It has an emotional and relational resonance that is created by, and can withstand, activities that are considered worthwhile despite 'being a bit off.'

While carers were willing to 'bend the rules', the materiality of hearth and the home did feature strongly in their strategies to remain orientated to the here and now, to one another, and to help combat their person with dementia's difficulty remembering their home. Consider Maria's anecdote about her husband not recognising their home, and John's description of his wife's pacing from room to

room, looking for children who had moved out decades earlier. In both these examples, Maria and John moved their person with dementia's bodies through space in ways to re-orient them to their belonging to, and the social set-up of the home as it was currently. Maria drove her husband, Jose, around the block again, calling out spatial cues such as street names. In a follow up conversation with Maria after this session, I asked her 'exactly what do you do to make this work?' My prompting seemed to instigate Maria's 'thinking through' of what she 'should do' to counteract what she worried was a 'new phase in the dementia'. She came up with the idea of having different ways to drive home that bypassed where they used to live, based on the idea that her husband was perhaps expecting to stop at that house instead of where they lived now. Based on our short conversation I drafted a visual representation of her explanation (Figure 1), which has been anonymised for this chapter.

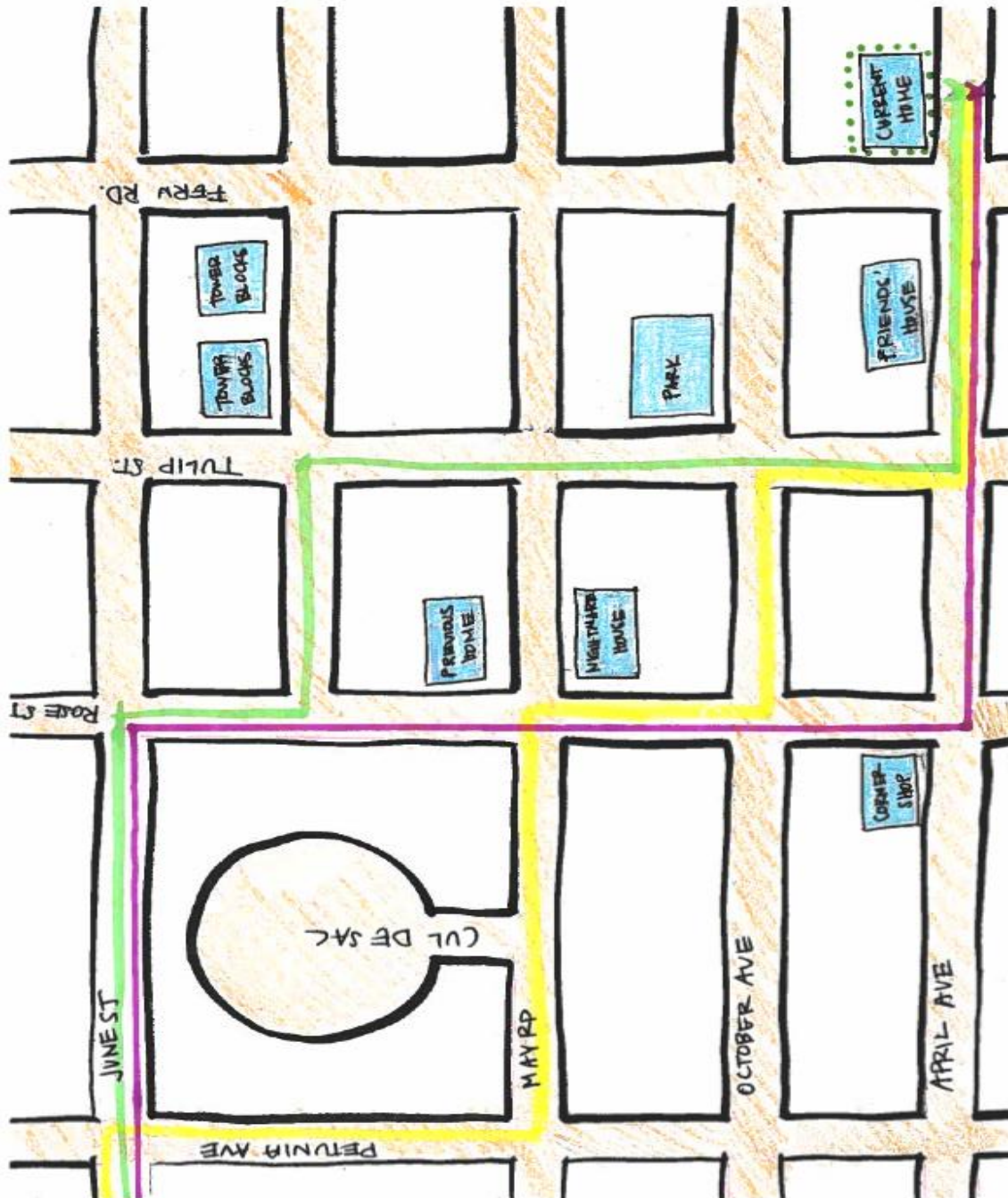


Figure 1 – Maria working to help her husband 'arrive' at home.

Three different coloured lines wind their way across the simplified map – the red line represents 'the way we'd always gone home'. The green and yellow lines represent alternative routes home that take advantage of particular cues in the

neighbourhood that might 'jog his memory' of their current home and avoid other triggers that might confuse him. For example, the green line, which first runs along 'June Street' and follows the red line, diverges from the original route and avoids their former home by turning to meet Tulip St. She said this was to gain a view of 'the tower block flats that he'll have remembered going up' and past a small green area in the neighbourhood and a house where they sometimes went to visit friends. The yellow route took advantage of the visual cues of the Cul de Sac gated neighbourhood, and though it came close to their old home, Maria said she wanted to pass 'the 'nightmare house' as he called it, one of those that doesn't look anything like the neighbourhood' on the corner, as well as the 'corner shop he still walks to' to trigger his memory of coming home, but not 'confusing him by showing him the old house.' Maria's technique and these routes take advantage of the outside world and its spatiality, and instead of trying to force her husband into their current house, Maria wanted him to self identify it as his home now.

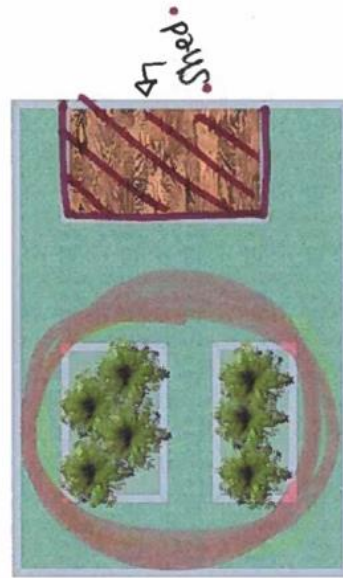
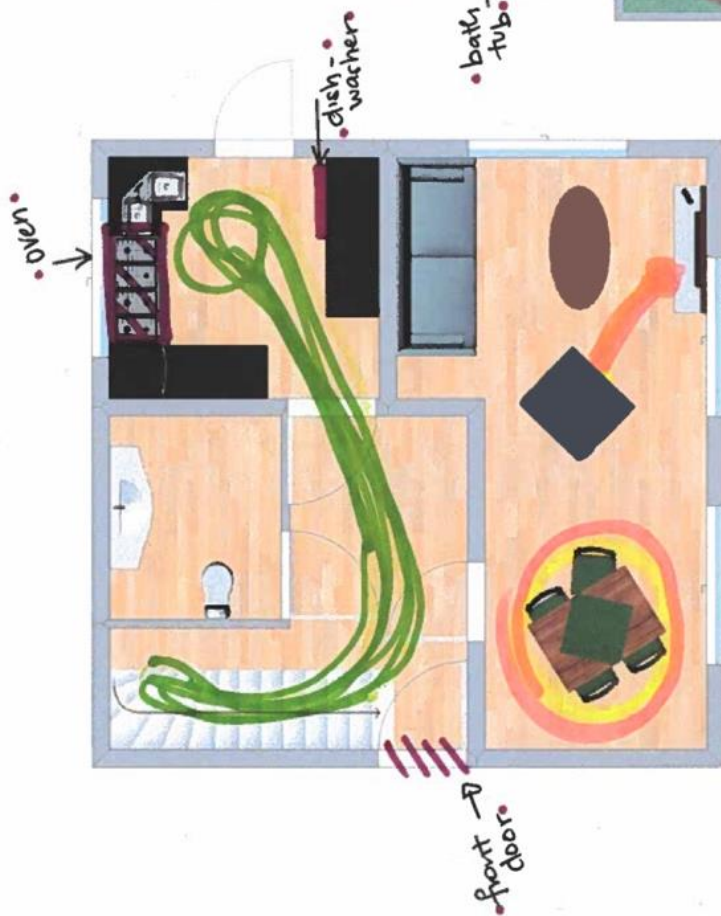
John's anecdote illustrated how he walked his wife through different rooms of the house to look at the home office (instead of a child's bedroom) and showed her pictures of those she was looking for. He did this when his wife seemed to stray into earlier memories of the home, evidenced by her acting out her role as a




mother to young children. John sought to show her the house *as it was currently*, and they then had tea together. His wife seemed to 'come around' through these strategies, evidenced by her having tea - perhaps an activity more appropriate for her position as an older woman living at home with a husband.

John's story mirrored an interview I conducted with a man named Howard, who cared for his wife, named Celia living with advanced Alzheimer's in their home. Figure 2, an anonymised representation of their home, illustrates the frustration Howard felt when his wife 'used to constantly pace around the house' before her dementia progressed to the point where she now spent most of her time in a wheelchair. Based on Howard's interview, the green line represents the area in the house through which Celia 'paced', as Howard called it. He told me how annoying it was when she 'would be up and down the stairs, around the kitchen – not doing anything, just in and out' as well as through the upstairs rooms.' Howard also explained that 'before she got the wheelchair, I had to be careful of her, you know, watch her all the time because she'd get in trouble'. Certain parts of the house became dangerous in his explanation: those marked in red, such as the front door, the stove, dishwasher, bath tub, were particular areas where 'she could hurt herself, or make a mess,' such as when Celia filled the dishwasher with dish soap instead of dishwasher tablets. Further, the door to their house, the boundary point

between the inside and outside, was a point of worry as 'she might just go out without me knowing if I'm not watching her, or leave it unlocked'. This echoes Buch's work (2015), but goes further in showing that in the contexts of dementia, boundaries of elderly people's homes were not only guarded against those outside, but also by care partners who identified the occupants of the house as a possible source, or victim, of unintended danger.



 = "Celia pacing", "going back & forth"  
 "just in & out"

 = Cereas made dangerous, "have to watch her"

"trying to calm her down" "she used to..."  
 = "gives her something to do"

*Figure 2 – Howard reorienting Celia to their home.*

The pink and yellow areas of the diagram, illustrate where Howard tried to 'keep her at the [dining] table, or in front of the television' to counteract her troublesome pacing through the house, or around its 'danger points'. He also explained that 'when she was going around like that, I'd try and get her out in the garden so she'd walk around it instead – she spent so much time out there...it was really lovely before her dementia really got hold of her.' This points to ways in which movement and walking became problematic by being constant and repetitive, 'going on' too long, but also in the wrong areas. Howard, like other carers, sought to soothe their family member with dementia – as well as their own discomfort 'watching her like that'. They did so by bringing them to stillness and transposing their pacing to areas less 'odd' and reminiscent of 'who someone was' and 'what they had always done' so that it might seem more normalised and resonant with their historical family life.

Sitting in his kitchen, on the bright spring day of our interview, I could see through the window where his wife now sat in her wheelchair, layered with blankets, facing their small garden. Howard told me that 'as sad as it is that she just sits most of the day, I feel guilty saying this, but it's easier for me...' The garden was just

beginning to show the green shoots marking the change in seasons, and while still mostly bare, brown and a bit untidy, it showed signs of the care it had previously received from Celia: planters and raised beds were visible through overgrown grass, and bird feeder hung from a small fruit tree. Even now, in these late stages in which his wife was almost entirely mute, Howard always 'made sure she can see it [the garden].' After we officially finished our interview, Howard and I went outside to sit with his wife and 'say hello again'. Reaching down I gently placed my fingers on the back of her hand, looking for an indication that I might be allowed to grasp her hand in a hello. Her eyes were set on the small plot of green she and her husband shared, but she turned over hand so that my fingers slid into her palm, and she gently slid her and my hand toward her knee, almost as if pointing to the view to which Howard oriented her every day.

In Maria, John and Howard's strategies we can see that the materiality of the home becomes a technology to re-orient and remind people with dementia of where they currently belong, who they are, the current 'social order' of their lives (Bourdieu 1977), as well as the *when* of where they are. Problems like those thus far described often coincided with remarks such as, 'she's not really my mum anymore, she'd never let things get so messy at home', 'I don't even recognise him sometimes', or 'It's things like this that just make you realise that what they

say about Alzheimer's being a long process of grieving is true.' Understanding the home as representational and constitutive of kinship and identity, can explain carers' frequent pain, confusion, and unsettlement in the updates they shared. Considering the importance of others within one's home links to my demonstration that relatedness and belonging-ness are crafted through doing things together in the home. Becoming disorientated to activities within the home and not recognising the house *as their own home, now in the present* seemed to bring up questions for carers about their people with dementia's belonging and embeddedness in their kinship networks, and to each other.

Maria took her husband's refusal to go into the house as a sign that he did not recognise *her*. Howard felt compelled to help his wife 'remember' her garden and spend time there as she always had so that her inhabitation of their home was normal, as opposed to potentially dangerous. And while John's wife's behaviour could be read as expressive of her relationship to her children, the behaviour's lack of synchrony with her status as an *elderly* mother was 'eerie' because it did not fit the relationship she had with her children currently. It appeared she was looking for a particular 'liveliness' (Allerton 2013) that was not the present, accurate liveliness a home shared only with her husband. Indeed, the strangeness and eeriness of people with dementia's disorientation to their home, its routines,

and the people within it, could, in turn, make carers themselves feel disorientated. In describing the strange behaviour of his wife for example, John described his own experience as eerie. The quiet and calm of a home occupied by an elderly couple was disturbed by the sounds of the wife, opening of doors, and her tenor of anxiety in not finding the children for whom she was looking. In this we can see how life could become surreal for carers as well, when disruptions to the established rhythms of when and where people were, became themselves routine.

Considering the danger to family connectedness that temporal and spatial disorientation to one's home posed, I thus position efforts made to help people with dementia to anticipate and understand the social significance of routines and their homes viscerally, beyond the intellect, as acts of care for their person with dementia, as well as care for themselves. This came out of carers' desire to keep meaningful and intimate relations alive 'as it was before' but with people who have unique histories and individual personalities which are known well only by having spent considerable, meaningful time together. Their strategies are characterised by an entanglement between relationality and individuality, as well as an overlap between time and space.

## Part Two: 'Needing to Go Out': Navigating the boundaries between safety and independence

*'You just don't know what can happen out there'*

During an evening support group a carer named Nichole told the group she regularly attended a story that she had

read in the paper recently – a woman with dementia got out of the house at night, was out – and her family didn't know till the morning, but they called the police who went looking for her, and they *couldn't find her for two days – days! – the worry!* And when they did, oh it was terrible, they found her in a ditch down by a stream...dead...they said it was dehydration and exposure...and I was reading this, and my heart just...oh, it's horrible.

After this carer finished, shock was apparent across the face of every person around the table, and my own throat was dry. The cold rain against the windows of the meeting room seemed all the more menacing and I noticed one or two of the carers glance outside as the group as a whole took a moment to recover. Stories detailing scenes as tragic as this were rare in support groups, but



typified other warning tales circulated in my interlocutors' support groups about the dangers which 'going outside' posed to the safety of a person with dementia. This was often posed in contrast to the space of 'the home', which was generally seen as place of safety, or a space in which safety could be more easily assured. The 'outside world' was often cast as daunting in its hugeness, and typified by the multitude of places where 'he could get lost' or 'I could get turned around' whereas the home was more often portrayed as 'safe'.

Gilly was a carer who had had a recent family crisis in which her father had been 'wandering again and didn't come home and it was past dark! We didn't know what could have been keeping him – he wasn't meant to have gone far.' Using the GPS tracker on his mobile, she and her partner tried to track him, but the reception was inconsistent,

We tried to call [underground and overground rail] stations to keep an eye out for him, but it [the GPS] only really gives you a general idea of where he is so we couldn't go and get him. He was ages away – I asked Sam [her partner] what's he even doing going there? We couldn't make sense of it. Finally we got on [the phone] with the police, and they put his tracking number on the police's phone and they found him. He had

a bottle of wine from Tesco and chocolate muffins. Sam and I drive over, and he's offering the police officers wine and I'm thinking to myself '*Oh, Jesus and Mary.*' Then we brought him home and he stayed up for 48 hours.

She laughed at the absurdity of this situation, before going on to describe the exasperation and fear she felt because:

I could see him on the map, but really, he could be anywhere!...We didn't know he'd been doing that – maybe this wasn't the first time he'd left the house at night, but this time he couldn't find his way back...and after I talk with my dad and he says to me, 'Gilly! I always go for a walk in the morning!' and I just....I had no idea...we've [she and her partner] got a new policy – to make sure the doors are locked at night to keep him inside and safe when one of us sleeps over [at her father's home] and now the carer that comes and stays some nights knows too.

Another carer nodding along, interjected that she had also started to lock the doors at night, but that this decision was causing other problems with her husband:

He still wants to go out, me locking the doors doesn't make him forget that, and I'll tell him 'oh you know, the door's jammed' but then he just paces around, room to room. The other day he got angry and told me he's been locked up.

At a different support group for carers, Marlene, a lively woman in her mid-50s, told the group that she had started noticing a urine smell and stains on the stairwell when she left for work in the morning. She thought that they had been caused by a neighbour's dog or spilled liquids from 'someone dropping their shopping coming home'. However, one night the week before, Marlene decided to follow her husband when he got up from bed at night

like he does all the time at night these days. And I watch him go through the front door, unbutton his trousers, and [laughing] just like that, he starts weeing right over the rails of the stairs! Free as can be – leaning back, weeing – and then he does up his trousers again and

comes back inside, and there I am just standing there, in the hall, he just walks by me, and I'm thinking – I'm so tired of course, so I'm half laughing to m'self – *Oh my God – it's been him!* ...He must be thinking he's been to the toilet the whole time – if I would've told him he'd been going down the stairs he'd 'ave looked at me...angry, you know.

Marlene chuckled through much of her scene descriptions and the group and myself responded in kind, some members wiping their eyes in a wave of amusement. She finished with '...how am I going to keep him from going down the stairs though? I think I'll have to try and lock the front door – get him off course – and follow him to make sure he uses the toilet *we have...*' She finished with a common refrain, '...if you don't laugh, you cry!' at which many of the other carers nodded.

In these stories, we see the surprise and shock inherent in many carers' discoveries that their person with dementia was leaving the house at night and going places and doing things that were 'strange'. Many carers were caught off-guard and their reactions ranged from fear and shock to amusement, as well as chagrin at wanting to 'keep him [their person with dementia] inside' in opposition to their person with dementia's own wishes and the tension in their relationship this could cause.

'Locking someone up' became an ethically contentious issue, to which I will later return. Recalling the previous section of this chapter, I suggest that wandering became problematic because the farther people moved away from the established routines and space of the home, the more potentially dangerous such movement seemed. For carers, 'what he could be doing', 'where he could be' and 'what he could be thinking' were all mysterious and potentially dangerous *in conjunction* with the wrongness of going outside at night. Further, the rational, the why, behind people with dementia doing things or going places outside became destabilised and cast as caused by disorientation, rather than based on reasoning untouched by the disease. We see this in Gilly's inability to make sense of her father's night time travel to a different part of the city, and Marlene's deduction that her husband was weeing down the stairs because people with dementia get confused at night. Thus, wandering was in part dangerous *because* it was caused by dementia.

The difficulty of spaces beyond the home also featured in people with dementia's discussions. A woman with dementia named Clara explained that she was nervous about a specialist dermatologist appointment her GP had made for her for the following week because:

I haven't been there before...his office is far away and I think I'll have to take two buses to get there, transferring three quarters the way – I've had a look at the bus lines. I think I can manage, I think I might walk the mile after the first bus to avoid the faff, so if it arrives late and I miss the connection I'm not waiting, but it's a bit pressured because the appointment is early – 10am – so if I get turned around [disorientated] or they're [the buses] late, then I'll miss it [the appointment].

Clara's description of her current worries about an upcoming challenge echo other people with dementia's hesitation about meeting with friends or attending appointments that were 'too far away'. Many explained that it was easy to quickly get lost on buses, or forget directions if walking through unfamiliar neighbourhoods. The outside was seen as challenging in comparison to the home, because their surroundings were often unfamiliar, and a space over which they often did not have ownership or control. They might encounter problems they did not know how to solve and were not able 'to take [their] time'. Making sense of the sequence of the bus stops, or having to 'rush across the road because the light's changed' was stressful, and dangerous because 'everyone's in such a hurry.' Many feared being hit by cars, scooters, or other people.

The uncertainty which large swathes of unfamiliar geographical space engendered for people with dementia echoes other research on older people navigating their neighbourhoods. Lee and Waite show that disordered, messy environments, and the awareness and safeguarding decisions they demand, are particularly cognitively taxing for older adults (2018). Their work proposes that the disorder of outside environments affects the inner cognitive state of older adults whereas commonly, carers and my interlocutors with dementia often saw a person with dementia's difficulty in making sense of the world around them resulting from an inner disoriented cognitive state. This perhaps highlights an interdependent relationship between inner and outer worlds, akin to the overlap and interdependence of the contexts of home and the outside.

Clara's anecdote also refers to temporality in her worries about the timing of her journey and arrival, indicating that navigating space is not just a matter of covering ground, but 'timing it right'. Temporal factors which complicated people with dementia's efforts to navigate 'messy' outside worlds arose in other conversations as well. During a meeting in late October, group members with dementia spoke about the change in seasons. A woman named Frances mentioned, 'I find it difficult when it gets dark early because it's hard to know how

much time you've got left, and when there's not much light it could be 6am or 6pm.'

Arnold, another member responded with, 'The older you get, the longer it takes!'

Francis asked, 'Takes what?' to which Arnold replied, 'Takes to do anything! Ha! [the group laughed along with him]...so I just keep to the house more in winter because there's less time to make it home.'

Francis and Arnold allude to 'doing less' during the darker months because beyond the bodily dangers posed by the outside, great distances took considerable time to navigate. This could be complicated by confusion about being able to accurately keep track of time. These sentiments were similarly echoed in carers' complaints about the daylight and time change: 'When it gets dark so early it confuses mum, and she wants to go home – even if it's still early and I've still things to do...' and 'I just find that I want to go out less, in the dark and the cold, and so I'm home with him much more...' What becomes clear is that the change of the season to winter and earlier sunset shrank the span of time within which people could do things outside, alongside the geographical range considered safe and navigable for people and carers. The outside posed an



additional danger as well: in trying to navigate the distance of one's journey, the unreliable sequencing of public transportation under mounting pressure of being late, some of my interlocutors with dementia worried they might need to ask for help. In doing so, they risked the disclosure discussed in the previous chapter because 'I need help with the bus! Just the bus!', or having to explain that they had dementia.

While the relative weight this worry carried varied among my interlocutors, with some said 'well, I just say to the driver – 'I have trouble remembering, dear, can you please tell me where my stop is? Stop there for me?'. This signals that trepidation about the outside existed on a continuum, but underscores widely held notions that navigating the outside world will probably be tricky and require help. Thus, for people with dementia, confusion, or 'getting lost' in the outside world, was often characterised as frightening not only because of bodily danger or distressing confusion that could ensue, but also because of the relational consequences that might result from being obviously confused in public, or needing to ask for help from kin 'to go someplace'.

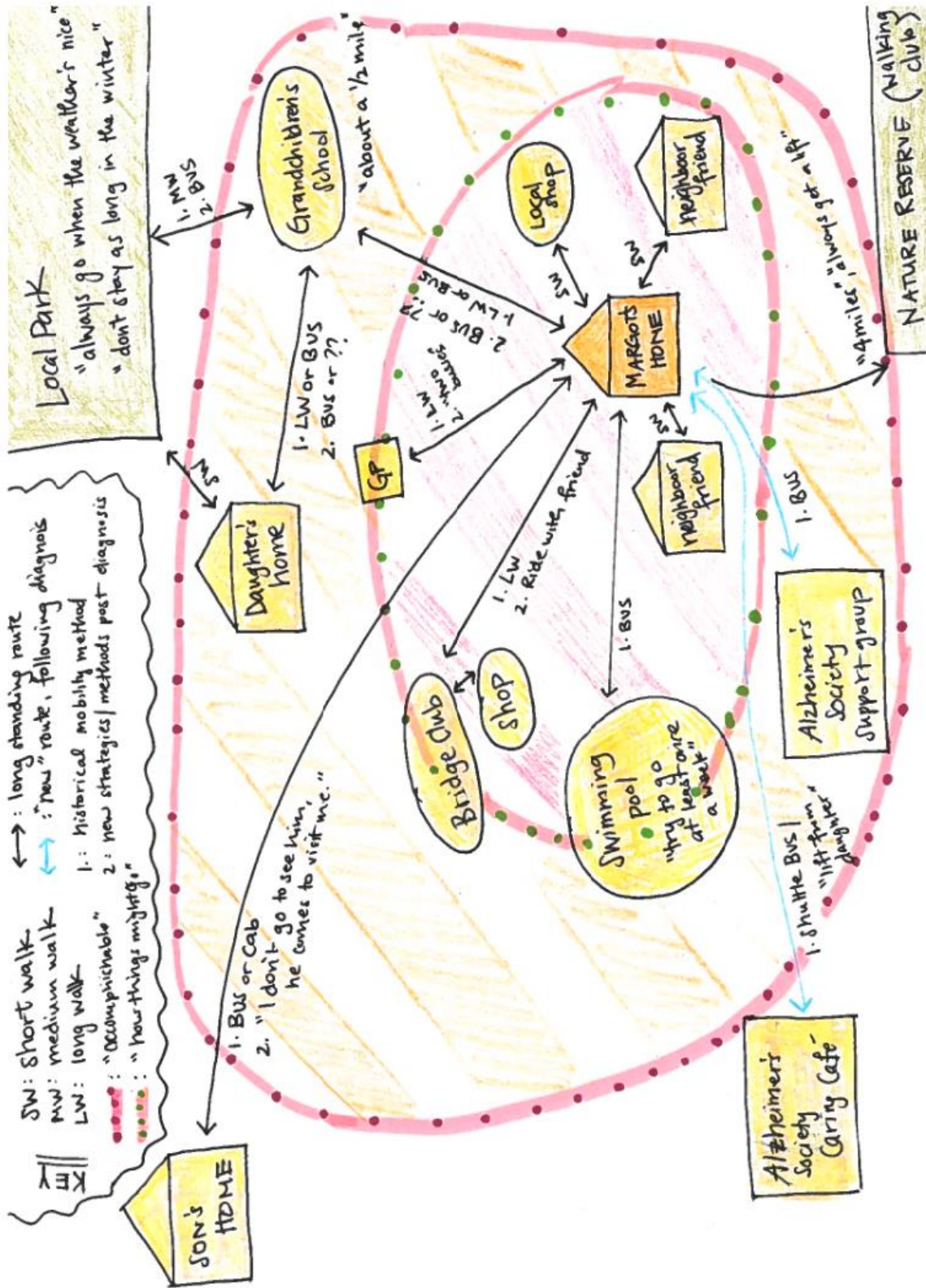
One might ask why, in spite of all these dangers posed by the outside, do people still leave their homes? Why?

*Risking danger: more at stake than bodily safety*

While carers and people with dementia described the home as a safe space, it could at turns become stifling and a place to which carers and people with dementia became increasingly tethered, which was alluded to in Part One of this chapter. While sun downing and wandering were described as divorced from the historical routines of the home, for many carers, they happened often enough that they became anticipated or expected. Carers feared 'not being there' – in the home and with their person with dementia, 'when something happens', and that they 'can't leave the house – I can't leave him on his own'. The burden of being a carer was acute and real (Andrén and Elmståhl 2008; Serrano-Aguilar et al. 2006; Zarit et al. 1980), and most saw their duties as a carer stretching indefinitely into the future. Conversations about 'how to manage being a carer' in the long term and in the present often revolved around the importance of leaving the space of the home for varying periods of time, often called 'respite'. Further, as the caregiving relationship between people with dementia and carers intensified and they both became progressively homebound, they felt frustrated that 'I feel like my whole life is at home' and 'The only person I see is her [or him].'

Carers' feelings are consistent with research on the marked and painful social isolation experienced by older adults, people with dementia and their carers (Holmén et al. 2010; Johansson 2017; Layden 2017) and the emotional loneliness caused by shifts in relationships with kin and friends (Mellor and Edelman 1988). Thus, seeing other people and leaving the home were positioned as ways to protect against social isolation and loneliness, and 'worth' the dangers that 'going outside' posed.

By 'seeing people and getting out [of the home]', my interlocutors also wished to inject temporal and spatial distance in their relationship with their opposite carer/family member or person with dementia, so that 'we're not together all the time'. Becoming increasingly tethered to one another was a threat to my informants' ever-present desire to 'stay independent', and thus, to the integrity of their relationship, as the burden of caregiving or being a cared-for person became the central aspect of their lives. People with dementia, in particular, wished to counteract notions that they 'can't manage on my own' and that they have become 'dependent.' Figure 3 depicts Margot's description in our interview of her 'world' since 'the dementia started.'



*Figure 3 – Margot's navigation of, and a resistance against, a 'shrinking' world.*

The first key point illustrated by the diagram inspired by Margot's experience is that people with dementia often felt the geographical range of their everyday lives shrink. The entire page represents 'everything I used to do'. The next smallest concentric circle illustrates what Margot and her daughter felt were currently safe, and accomplishable distances considering her current abilities. The smallest circle is a projected border based on Margot's thoughts on 'how things might go' in the future. As indicated by the red lines and shading, Margot most prized regularly picking up and seeing her grandchildren from school, and bringing them home, often via the park, thereby 'helping Judy [her daughter]'. The number '1' next to these routes indicates her established routes, which was using a 'long walk' or the bus, depending on the weather. However, as Margot's dementia increased, she explained that she now 'took the bus more often' because I find it takes me longer to get there, and I worry about getting lost,' but that she still 'walked with the grandchildren, because they know the way by now – even if I were to forget!' Margot remarked that she and her daughter 'had brainstormed' these plans together. Here, Margot emphasises what she does with and for family as important, akin to other relationally rich destinations such as the Bridge Club, her neighbour's house, and increasingly the Alzheimer's Society services she attends.

At the same time, Margot also emphasised that she does her own shopping near home, goes swimming regularly, is part of a walking club, visits the nature reserve, and instead of asking for a lift from her daughter to the big superstore, prefers to 'go along' when a friend of hers was going. The previous chapters' discussion of identity based on past accomplishments and everyday routines underline Margot's investment in 'doing things on my own' and maintaining social ties beyond the home. She sought to be a help, and not a burden to maintaining her and her daughter's identities beyond the label of 'carer' or 'person with dementia'.

Mapping out 'support networks' to get help in meeting care needs became important to 'getting away' and creating relational distance between a carer and person with dementia. Carers' emphatic discussions about the 'need for respite' always meant a separation in space between a person with dementia and a carer, in which either 'went away [from the space of the home] for a while'. While leaving the home might seem to contrast with the relational connectedness created through home-based 'being with' activities explored in the previous section, 'apartness' is, in fact, aimed at the same end. Many carers commented that 'really, you can't survive without it'. My interlocutors recognised that too much closeness with each other was as detrimental to the integrity of their relationship as being out of sync, because it dissolved the individuality of each person. 'It's like we're

the same, even though I don't have dementia. We do all the same things...so what's the difference?' was a question I once heard posed in a support group for carers. Commentary such as this signifies an active resistance against carers and people with dementia becoming 'faded' versions of themselves.

In the calls and desires for separation, we see that an ethic of *being with* (Caldas and Berterö 2012) as a form of care requires calibration: too much and it becomes harmful to wellbeing and relatedness. This demonstrates that individuality is necessary for relationships because relationships require *two separate selves*- a relationship can only exist in the space, the divide, the difference between two people. I suggest that in metaphorically walking away, in striving for separation, my interlocutors were, in fact, seeking a way to create a divide, a vantage point at which to turn around and reach across a space of separation to one another. In the same way as too much closeness prompted movement away from the relation, the elastic tension of this relationship caused a chance of return to one another when carer and person with dementia were pulled apart by 'doing other things'.

Another reason that going outside was considered important was because 'keeping someone inside' or being kept inside often disturbed my informants' ethical sensibilities. In a number of group conversations, carers spoke about their

guilt in confining their people with dementia to the home. On a few occasions, an Alzheimer's Society facilitator explained that, legally, they were not allowed to 'lock someone in the home' and could 'get in trouble with the authorities if they were found to be depriving someone of their freedom', citing DOLS, the Deprivation of Liberty Service, while sympathising that 'it's difficult to do the thing that keeps someone safe, but not deprive them of their liberty'. This usually created a noticeable pause in the group as carers contemplated this information. In some meetings, carers debated whether locking the doors 'was something you could be in trouble for – I only do it at night, when I know he might go out and I wouldn't know...', 'Yes, only at night because if he goes out, who knows where he could end up or what could happen to him?', and 'Of course, only when I'm home too. It isn't as though I leave for the shops and lock him in...' Carers wondered about their right to control their person with dementia's whereabouts, knowing that the person they cared for usually resented this control. Indeed, in many people with dementia described their annoyance of 'hovering' children or spouses 'always asking me where I'm going' and bucked against 'being watched all the time' while they were at home. While carers weighed the ethical risks of 'locking him up' against the physical risks of a person with dementia leaving the house at night unattended, what emerged was that this was not necessarily a debate about legal ethics, but relational ethics. Decisions were often made in favour of 'keeping



him in' and justified because it 'was only at night'. Notably, these decisions were justified because they were the result of behaviour that offended the ethics of a family's social and temporal order.

On a few occasions, carers spoke to me about 'what she can't do anymore' while their person with dementia sat next to them, who then became, understandably, increasingly irritated and exasperated and admonished, ' *You* say I can't do those things! *Your* opinion!' At the heart of this, and earlier ethical dilemmas, is the query of *who gets to decide*, and connects with the next chapter's discussion of legal capacity. People with dementia did not want decisions made for them, and carers did not enjoy making such decisions, because doing so often changed relational dynamics. Such changes were often taken as a loss, 'another thing [that is] going' and signified that 'we aren't equals anymore'. Carers saw this as a sign that their person's dementia was progressing. Here, the boundary points between the home and the outside world, as actual spaces and sites of control, 'emerged as places where older adults enacted their broader ambivalences and struggles around the looming reordering of their social personhood' (Buch 2015: 41). Thus, many carers and people with dementia alike identified the importance of 'going out' and sharing the power to decide who crossed into, and out of, the spaces of

their home as an integral part of a balanced relationship, and their own independence.

Having considered my interlocutors' motivations for leaving the safe space of the home, I now describe the tools that helped them to navigate the distance between home and where, and to whom, they wished to go.

*'Getting out of the house' while 'knowing where he is': GPS trackers and mobiles*

GPS tools and shuttle and taxi services were used by carers and people with dementia to help maintain their 'normal' plans and routines outside the home. These included meeting with friends at the pub or the community centre in the afternoon, doing the shopping, walking the dog, or going cycling during the day. Many carers' concerns about these 'normal' activities emerged as their person with dementia's disease progressed and usually after 'something's happened', as alluded to in the anecdotes detailed earlier, which made them 'wonder if he's really able to manage on his own'. Carers contemplated how to 'keep him safe when he goes out – because he needs to [go outside], of course, but I just worry' or ensure that their person with dementia could be found when they left home. My informants with dementia especially commented on the need

for 'going out' strategies as they noticed others' suspicion that they needed help, requests that they 'stay home', or more frequent offers from others to do things for them, such as accompany them places or offer rides. GPS trackers and shuttle and taxi services were, however, imperfect systems and tools that often created other forms of uncertainty or risk. I suggest that a willingness to deal with the 'hassle' of these systems is an acknowledgement that concerns about safety did not trump the necessity of and right to stay mobile and leave the home.

Common responses to GPS trackers were usually a weary acknowledgement that 'tracking' their person with dementia would be helpful, but that the tools in the Alzheimer's Society product catalogues were not user-friendly or reliable, and that GPS tools or other technological tools were inevitably 'too complicated for me!' In looking over products before the start of a meeting one day, one carer commented to another that 'I tried using that [a GPS tracker] too – doesn't work, a waste of money really'. The refrain that 'they're too difficult to figure out – I don't understand all that new technology!' often came from older carers who were spouses and often deemed technology as beyond their ken, as noted by other work on technology uptake amongst older people across European settings (Tacken et al. 2005). Carers who were children or nieces and nephews of a person with dementia were often much more eager to learn about modern technological

solutions to the 'tracking problem', and traded recommendations about which tools they had tried.

In one carers' group, of which half the members were children carers, a lively and optimistic group discussion about the usefulness of GPS trackers followed another carer's update about noticing that his mother 'doesn't seem to know all the places she's walked to for years!' After the meeting, I spoke to a few of these younger carers about my research into other tracking devices beyond those in the catalogues. I mentioned 'Tile', a GPS-embedded keychain chip that is marketed to track possessions. A Tile's location is tracked through a dedicated app on a smartphone, and its website touts 'Give your memory a break' and 'Ask others to help: Still can't find your Tiled item? Expand your search using all Tile apps in our community' (Tile 2016). None of the carers had heard of it, and a few seemed very interested in its potential, writing 'Tile' down on that meeting's flyer or looking for it on their smartphone's app store as we spoke.

At the next month's meeting, one of these carers, Lydia, brought up 'Tile' during her update to the group. She went on to explain that she had discussed it with her sisters, with whom she shares caring responsibilities. She described with pride how

Dad still goes out everyday, looks nice – he’s got friends everywhere, and likes to play cards, so he goes out to meet his friends, the barber’s – he’s not going to stay home! So, we knew we had to figure out something...and so I got on Amazon, and ordered a Tile, what Lilian mentioned last time...it came a few days later...really easy. And here [holds up her phone], I can just pull up the app and see – yes, see? [points to the screen of her phone] – that he’s sitting right outside [in the room next door where the Café was being held, as the carers support group met]! We put it on his keychain, it’s small and looks quite normal so he doesn’t wonder at it, and Dad *never* goes anywhere without his keys. So, now we can see where he is when he’s out of the house!

The carers responded to Lydia’s excited review of Tile with questions about how much it cost, what it looked like, and how it worked. At these questions, Lydia jumped from her chair and hurried to the next room, returning a minute later with her father’s keychain with the Tile attached. She passed it around the group while explaining that its best feature was that

We've [she and her sisters] all got the Tile app and have plugged in Dad's code so we can all see where he's gone to. It's less stress than calling each other back and forth when he's late because we can just pull it up, and there he is! I can always see him on here!...which would've been helpful a few months ago when I came to pick him up to come to the Cafe, and he'd gone off to friends instead!...We're less worried about where he could get to...don't have to ask him all the time, and make him mad...if he gets lost, or forgets the way home, we're sorted.

Her enthusiasm and relief were infectious, and Terrence, another of the carers I had spoken to at the previous meeting, seemed impressed. I later learned that he ordered a Tile device for his mother the following week. He told me that '...it makes sense – because my sister and I share looking after mum – well, my sister does more really, she sees her day-to-day, but this way we both know what Mum's up to.'

Several elements of these carers' excitement about this GPS tracking tool are notable. Lydia explained that Tile used Bluetooth 'networks that are already out there, really, so it always shows up'. This demonstration of tech familiarity, that

while not entirely accurate, denoted a certain ease with ideas behind the device indicative of the divide between 'young' and 'old' carers' general willingness to entertain tech solutions to challenges in caring for their relative with dementia. Further, her description of networks 'out there' also echoes earlier discussions of my interlocutors' conceptualisations about the usefulness of particular tools and strategies because they externalised knowledge about time and location. Lydia and Terrence both highlighted the importance of Tile's ability to map her father's location in a way that was accessible not only to them, but to their siblings as well. Their entire familial care network could then see and monitor a parent's daily movements and activities, substantiating the support network carers were encouraged to find and to mitigate stress because 'now it's not just up to me'.

Interestingly, beyond harnessing a relational network to 'keep track' of someone with dementia, Tile also highlighted the way in which this shared network relied on knowing what Lydia's father's 'dot on the map' meant beyond geography. She mentioned recognising particular coordinates as his barbers', which 'reminded [her] that he was having his hair cut that day'. She pointed out not needing to communicate these details to her other sisters because 'they'd see it too', implying that they would also understand the social significance of what his location meant. The GPS device seems to have helped assuage Lydia's and Terrence's anxieties

about future dangers by effectively shrinking the uncertain geographical range and variability of the 'outside' world. Lydia and her sisters' relief in part stemmed from being able to consistently see their father being in the right place, such as the barbers, and at the right time, a weekday afternoon. In a dot on the screen of the app, their father was portrayed as 'okay' instead of straying to disorientation. In the same way that people with dementia's eerie disorientation could make a carer's orientation to their home surreal, so could proof of their 'normal' positioning in the world re-orient a carer: indeed, Lydia was reminded of her father's plans in seeing his location.

Lastly, by hanging it on his keychain, Lydia and her sisters were relieved at its unintrusiveness, which meant that they did not need to explain to her father that he was being tracked. Echoing ethical discomfort with keeping their person inside and surveilling their actions, for many, particularly the spousal carers, these ethical concerns extended to tracking their person with dementia as well. While, for many, concerns over safety were paramount, corroborating other work on how decisions about GPS tracker are made within Israeli families (Landau et al. 2011), carers sought strategies that avoided undermining a person with dementia's autonomy. This differs from Landau et al.'s findings that carers did not involve their relative with dementia in decision-making because of a lack of trust in their relative with



dementia's capability to make this decision, as opposed to wanting to protect their privacy and autonomy. My material shows that GPS trackers like Tile allowed many carers to side-step the discomfort of talking about their worries and ethical discomfort at asking 'about where he's getting off to' or 'asking him to wear a big GPS watch' with their relative with dementia. They also acknowledged understanding that their relative with dementia 'wasn't keen to wear something like those MedAlert things, they're like a big sign: *'Oh, I'm old, I need help!'*

Carers who were children and did not live at home with their parent with dementia most often implemented concealment and GPS tracking strategies and tools, again diverging from Landau et al's work, which found this responsibility most often falling on spousal carers (2011). In this we can see how children carers skilfully evaded taking an authoritative role in deciding or 'giving permission' to a parent with dementia to go out. In so doing, they sought to avoid obvious re-negotiations of the power dynamics in this relationship caused by visible control over their parent's time and movements, and perhaps also over men's time and movements outside the feminised space of the home. Perhaps this is because, otherwise, relational dynamics might be flipped and come to mirror those between parents and children, wherein parents are seen to have the authority to decide what is safe and give license to children's movements (Chaudhury et al.

2017). What also emerged is that children carers were also less likely to have direct conversations about 'where you're going' and tracking devices with their fathers, as opposed to mothers, and more likely to use trackers on fathers while asking their mothers to keep them apprised of their comings and goings. I suggest that these approaches were informed by the gendered associations of the home and the outside, as well as notions of 'who belonged where'. Daughters seemed less keen to upend socially embedded dynamics of authority by asking about or curtailing their fathers' activities outside the home, and also seemed wary of disrupting habits that were indicative of their historical identity as a person, but also as a man. Terrance, described above, was one of the few carers who 'tracked' his mother, and children carers' more common approach to speaking with their mothers about on-going worries and requests to 'stay close to home' might also be indicative of different ideas about the authority women, particularly elderly women, have over their movement outside and away from the home.

Interestingly, spousal carers, who were also by majority women, more often sought to downplay their worries about, or their desire to know, the whereabouts of their spouses with dementia. They used tools that were less straightforwardly targeted at tracking and instead at creating reliable communication, such as the use of mobile phones. These were often the carers who said they 'would never

track him without asking', not because it seemed too challenging a technology, but because it was an ethical affront. I link this contrast to children carers' approaches to many of my coupled carers' descriptions of their relationships as having been based more on collaborative decision-making. Take for example, Aminta, a carer in her early fifties who cared for her husband, Richard. During a group session she described how he went on frequent and long bike rides around the London area, a hobby he pursued 'for twenty years! Since he retired.' She felt his bike riding 'is very good for him', citing commonly-held ideas that exercise is beneficial for cognition (Barnes et al. 2007; Abbott et al. 2004). She, like many carers, worried about 'letting him go out' but in the same breath recognised that asking him to stay home would 'mak[e] him go mad!' In her update, she emphatically impressed upon the group that she was happy that he was 'still able to go out' and that for the time being 'yes, I think he's safe, he knows the way home'. She said that she and her husband had recently talked about him taking a mobile phone with him when he left the house so that she would call him if she wanted to know where he is or if he's late coming home. Aminta mentioned that she 'thought of the mobile phone because I just felt sneaky thinking of putting one of those GPS trackers on him, and I don't think we need that yet' and a few of the other carers nodded vigorously. Aminta was careful to explain that 'he's always made the big decisions – we've always talked things through'.

Discussion about mobile phones also featured in many people with dementia's contemplation of their disorientation as well. George, the man who in the previous section described his method of using his mobile to keep track of appointments, said his 'smartphone is brilliant. I can always see exactly where I am' and, like Lydia, pulled out his device to show Google Maps to his fellow group members. He pointed out the blue dot on the screen, remarking:

See, that's my location right there. And you can put in where you're going to and it'll tell you the buses. Remarkable, since having it [the mobile], I've been all over. When I go to visit my nephew, I've saved his address, I can sort myself out, and then he and his wife don't have to drive, they're so busy with the children.

The group and group facilitator commended George for 'sorting himself out', reinforcing widely-held notions about the importance of autonomy and independence. In another group, Tracy, a woman with dementia, explained that her son

recently bought me a mobile. He says he's worried about me out on my own, and wants me to be able to call. I had trouble coming home from the GP's a few months ago. I don't think I need it now...we talked and agreed before that I'll only go to places I know, and let him take me other places, but really, by the end of it, it was just easier to let him give me the mobile. That way he has peace of mind, and really, its not such a difference to me.

While concerned about mounting disorientation as a sign that one's disease was advancing was discussed with worry by people in my fieldsite, we see that protecting the stability and historical dynamic of their important and intimate relationships was their tantamount concern. Aminta did not want to risk questioning or limiting her husband's independence, thereby straining their relationship's status quo. We also see that people with dementia made decisions that, while on the surface may seem passive or as though they were 'giving in', such as in Tracy's case, were instead founded in practices of care. Her agreement was made to avoid causing her son undue stress, underscoring ways in which people with dementia are 'active facilitators' in their relationships (Jenkins 2014: 17). Indeed, while George's family did not suggest or ask him to use a mobile phone or Google Maps' GPS tracking function, he nonetheless 'sorted himself

out'. As a man who had never married and who lived alone, and prided himself on his independence, he did not want to ask for extra help from his busy niece and nephew or for 'them to start worrying'. These acts of care emerge as acts of recognition of one another, an important indicator of being 'still there' in dementia contexts (Taylor 2017). Help offered and received among my interlocutors took into account the value others' placed on being independent, as well as people's resources of time and energy to be able to help. They also signal gendered ways of showing care. George, as a man, centred his practice of care on his autonomy and independence - customary masculine qualities, whereas Tracy, as woman and mother, decided to 'go along' with her son's idea to protect their relationship. These tactics coincide with research on gendered forms of personhood and identity in that women's personhood and identity are grounded more deeply in relationality and 'relational competence' (O'Connor 1995) and men's in autonomy. In sum, these examples highlight that 'going out' necessitated an active navigation of one's social worlds and their requisite norms.

### *'Sorting myself out': Shuttle Buses and Dial-A-Ride*

In line with George's desire to 'sort himself out', people with dementia very much relied on specific transportation systems to help them navigate the outside world

and go places, namely the shuttle buses that brought people with dementia to Caring Cafés, and the Dial-A-Ride service, a local council-sponsored taxi service for people with disabilities. Indeed, transportation surfaced as one of the most consistent and fervent topics of discussion in support groups for people with dementia, and communal Alzheimer's Society services. Their significance lay in their position as systems that operated outside people with dementia's familial networks. Recalling Margot's avoidance of asking her daughter for lifts, in using these systems, people with dementia sought to avoid dependence on kin. These systems were imperfect, however, and not offered evenly across all boroughs, and their moments of breakdown often underscored the ways in which the temporal and spatial elements of people with dementia's lives often came to be under the control of others'. In so doing, they highlight that independence is mutually constituted in the context of dementia – people with dementia seen as needing to be supported to remain independent.

Over the course of my fieldwork, a shuttle bus service arranged by the Alzheimer's Society for taking a number of attendees with dementia to a Caring Café was threatened twice, due to changes in funders' priorities. Each time, the possibility that the bus was going to be cancelled was met with outrage on the part of the clients, and remorse and frustration on the part of staff and volunteers. When this

first happened and Alice, the Alzheimer's Society staff member who ran this Café, announced that the shuttle would no longer run, an attendee with dementia asked, 'Well, how on earth are we going to get here? Now that I've got my walker, the bus is too difficult, and the stop's too far away from the Centre anyway.' Another carer commented, 'I won't be able to keep coming along – my nephew can't take me every time – he's always out of town. I'll only be able to come when he gives me a lift.' Alice answered, sharing in the clients' exasperation, 'We're so sorry about this, and we're trying to come up with a solution, but we had to let you know now.' After the Café ended that afternoon and the volunteers had tidied up the room, we discussed the shuttle problem amongst ourselves as well. Outrage was similarly felt, and one volunteer suggested that, 'We just pay for it ourselves!' People with dementia, staff, and volunteers were all upset because it was well understood that the shuttle was the only way many attendees could feasibly attend the Caring Café. In this, the fragility and contingency inherent in the systems my interlocutors with dementia relied on to avoid becoming dependent on family was laid bare.

While the Dial-A-Ride service was not explicitly connected to Alzheimer's Society events and therefore not dependent on their funders, it nonetheless presented a similar challenge to people with dementia's efforts to 'sort myself out'. Molly, a



woman with dementia, described the odd inner workings of the Dial-a-Ride service. She explained that the previous day

it picked both me and Millie [another member of the support group] up, to go to Singing for the Brain, but then sometimes they send a separate car for each of us, so, I never know if I'm going to see Millie in the car, or at singing! They also won't take long-standing reservations, like every Friday at 1pm, so you have to call them every time to ask them to come, but then sometimes they'll already be booked up.

Other people who used Dial-a-Ride said that it was

difficult to know when exactly they're going to come. They give you a time range of an hour or so. So you end up having to book hours before you're actually meant to be somewhere to make sure you aren't late, and in the meantime you're just at home, having to be ready whenever they call.

Despite the intermittent reliability of these services, people with dementia still described them as useful because 'it's a relief not to have to be stuck at home...when you can go out on your own...much better to be independent'. While I have drawn out gendered differences apparent in carers' strategies to keep their relative safe outside, there was an absence of clear gendered divisions in the views of my informants with dementia concerning the importance of mobility systems they could 'sort themselves'. Men and women alike emphasised their value, despite their 'headaches'. Echoing the group's response to George's use of his maps on his smartphone and Margot's use of the bus, I suggest that people with dementia used mobility services to help them untangle their reliance on their children or friends to 'get out'. In so doing, however, the organisation of their time often then hinged on the decisions of Dial-A-Ride drivers and call centre employees, and many people felt 'forgotten' and incensed when they were, in fact, dropped off a ride roster without recourse. My interlocutors' experiences echo work on the control exacted on public patients by the Argentinian state through temporalities of waiting for services, which also established people at the bottom of social orders (Auyero 2012). Perhaps more pointedly, these experiences of waiting and unreliable service speak to research on the increasing privatisation of the NHS and related governmental services (Day 2016) in which personalised care is often made impersonal (2017). In using these systems, people with dementia's

total control over the when and where of their activities remained elusive. Notably however, they were often still ranked above placing this control in the hands of kin, or 'giving up' on going out. In waiting at home, alone, for a ride that was 'usually going to come', an element of relational independence was won and thus a balance in the interdependence between kin maintained.

## Conclusion

In this chapter I have explored how my interlocutors managed ongoing challenges in their everyday lives within and outwith their homes, and what else is disorientated or endangered when a person with dementia loses their bearings on time and place. My findings show the entanglements between time and space, the home and outside, autonomy and relationality, closeness and distance, and power and partnership. Concerns about people with dementia 'doing things right' or behaving normally show that neither space nor time are comprehensible without each other. They are correlative, 'cannot be disentangled' (Munn 1992:94), and each is predicated on the other. As such, both the *when* and *where* of people's actions matter in reckonings of relatedness, and marking particular sites as relationally meaningful.

Because of the cognitive challenges posed by their illness, moments of disorientation cause people to 'leave' the site of their current homes. They seem to, at times, live instead in vestiges, memories of former houses, not realising that time has moved on. Carsten writes that the vestiges of previous homes 'are embedded in the imaginations and personal biographies of the inhabitants who carry them, sometimes unconsciously, from one site to another' (Carsten 2018: 114). She cites Patrick Joyce, 'In this sense, we never really leave our houses, especially the first one' (2014: 84). Carsten and Joyce are speaking here about people moving out of houses and into new ones, taking with them traces of former homes.

Much of what carers do in response plays off the embeddedness of houses in people's imaginations and biographies to then bring their relative with dementia back home, back to the present. In this, connotations of 'vestiges' as something of the past become blurred; carers use reverberations of current homes to realign disoriented people's recognition and familiarity with where they live now and, importantly, *with whom*. Considering the house *as* kinship (Carsten 2004; Bloch 1993), in my informants' efforts to 'never really leave our houses', they too seek to never really leave their relatedness to one another. Indeed, even efforts to

sustain carers' and people with dementia's freedom and ability to leave the house and 'get away' from each other are predicated on a temporariness: geographical and relational distance is sought so that people can return. My interlocutors' practices accentuate that homes, and their vestiges, are tethers between temporalities but also between people.

I have used the word 'strategy' frequently in this chapter, highlighting that what my informants I worked with do in the present, in response to challenges wrought by dementia, are practices of care with a goal, a means to an end. I argue that the 'end' of these approaches is 'still being there': the preservation, mitigation, or at least deceleration, of a person with dementia's disappearance as a person. In contexts of dementia, what also went missing was, at turns, closeness and distance between a carer and person with dementia, a balanced tension between relying on one another and managing on one's own. Considering the tension between relationality and individuality at the heart of Western personhood, the experiences of people in my fieldsite show, keenly, that maintaining personhood is no mean feat: it requires showing up to the right place, at the right time, doing things in sync with others while also pursuing activities alone, cultivating close affinity but avoiding over-dependence, and both giving and receiving help.

Here we see that personhood is a relational project, a negotiation of the when and where of people's whereabouts and activities. As such, dynamics of power and authority become implicated in complex ways and strategies to prevent, mitigate and correct disorientation were diplomatic projects in which all parties sought a balance of power that maintained people's integrity as persons and good relations. This is because the temporal and spatial aspects of a person's whereabouts can, conceivably, be manipulated and controlled (Bourdieu 1977; Munn 1992), but also defy regulation in moments of 'eerie' disorientation. Further, most often, family members did not want to exact control over their relative with dementia's whereabouts, thereby disorienting historic patterns of authority in these relationships. In this we see a divergence from Bourdieu's emphasis on the inequalities created through 'strategic manipulation[s] of time' (1977:6), and also space. Most people with dementia and carers in my site worked hard to *avoid* creating inequalities of authority in their relationships, and to maintain historical 'appropriate' inequalities such as those between parents and children, that might result from alterations to when and where people did things. Gender norms and roles also play a part in whether strategies of concealment or direct conversation were chosen to address desires and needs to curtail or surveil people's activities. My interlocutors sought equality and avenues to keep things in line with 'how

things have always been', to avoid falling into roles predicated on carer/cared-for dichotomies (Jenkins 2014).

There were, of course, instances in which carers were relieved at being able to control or surveil their person with dementia's activities, such as Howard's embarrassed admission that his wife's transition to a wheelchair had made 'life easier' because it halted her pacing, or Lydia's excitement over her surreptitious GPS tracking of her father. What is notable in these instances that seem contrary to other others' efforts to 'be on the same page' and 'promote autonomy', is that this control was in all cases still a way to bring the habitus (Bourdieu 1977) of people with dementia back into alignment with the 'social order' of family life. In so doing, 'their being in the world' (Caldas and Berterö 2012) was made comprehensible and relatives could go beyond 'doing' things together to *being with* one another (Caldas and Berterö 2012: 245). Indeed, Howard made sure I met his wife, and that we spent some time all together on the patio, where he could safely keep her in proximity to the garden. In this, the normative 'social order' was not a tool of control, but the realm in which people, their integrity, and their relationships, could be kept safe.

## **CHAPTER 4: Navigating bureaucracy, safeguarding personhood:**

### **Planning for an uncertain future**

I was volunteering at a Caring Café in South London, greeting Café guests as they arrived and preparing their tea or coffee to their preferences. The mood in the community hall was light and almost giddy as the bus from a nearby care home arrived, and a number of other regulars came in from the wind to find seats. I made friendly conversation with many of the attendees, asking after their families and explaining the planned activities. I met Helene, a woman with early-stage dementia, who came with her husband, Leopold. I had developed a friendly rapport with the couple over the previous months and we cheered over the change in the weather. They remembered that I had mentioned plans to visit family in Austria over Easter, and asked how my trip planning was coming along. In turn, I asked them what plans they had made for the summer. She replied, 'Well, we usually go to visit my son in Germany, but...well, we'll see...' with a squeeze of my arm, while her husband added, '...it'd be nice, but...we'll see...plans will



come...but are you staying in London all summer or will you be back to uni?' Helene and her husband's responses were friendly and attentive, but subtly indicated discomfort when speaking about plans for several months ahead. Their pauses implied a future unable to progress in line with the past, for reasons difficult to name, discuss, or predict.

This chapter is an exploration of my interlocutors' experiences living with dementia through the lens of 'the future.' I examine how carers and people with dementia imagined, spoke about and prepared for their futures or often, worked to indirectly imagine, avoid speaking about, and evade direct and detailed planning of their future. I build on previous chapters to show that my informants with and without dementia sought to mitigate the extent of changes the disease wrought to their ability to 'stay independent' and 'be who I've always been', and remain connected to family and their social worlds. I show that while the future was an uncomfortable topic for many, support groups were significant places where they learned to strike a balance between autonomous decision-making and familial harmony so as to safeguard their futures against uncertain, potential crises.

The overarching focus of this chapter is the seeming contradiction underlying my informants' engagement with the future, in that they avoid speaking about their general future specifically, but are very clear about wanting certain aspects of their lives to remain unchanged into the future. I argue that carers and people with dementia use bureaucratic and legal processes to engage in a careful cat-and-mouse game that obscures imaginings of difficult and sad futures, while at the same time allowing them to protect against and mitigate expected losses of control over one's home, finances, relationships and independence. These losses can be seen as significant disruptions to one's biographical narrative (Bury 1982), complications to the project of 'successful aging' (Lamb 2014) and ideals of western personhood in which control over aspects of one's life and decisions is paramount. I suggest that my informants' approach to the future is grounded in a desire to bolster a person with dementia's ability to 'still be there' in temporalities beyond the here and now, despite expected cognitive diminishment and loss of control.

I seek to complicate Western ideals of independence and autonomy through an examination of my interlocutors' novel methods of stretching the temporal domains of decision-making and capacity, and the home as a private site of both kinship and independence (Buch 2015). Carers' and people with dementia's

renegotiation of decision-making after 'capacity' has been lost contributes to the overall argument of this thesis. In contexts of dementia, maintaining one's autonomy into a future marked by cognitive decline demands new ways of being related to others that acknowledge and mitigate dynamics of dependence. This is because overt, sustained dependence is a threat to the personhood of carers and people with dementia alike (Buch 2013, 2015; Kittay 1996). While dependence may seem at odds with independence, I argue that future independence in the context of my informants' lives is shown to be, paradoxically, a relational construction. People rely on this relationality to carry forward independence and decision-making into future temporalities when capacity can no longer be demonstrated in the present.

As much of this chapter focuses on relationality between family members, I draw on work exploring the moral importance of care in kinship (McKinley 2001; Faubion 2001; Sahlins 2011). In dementia contexts, 'good care' is understood to be that which 'is highly respectful of personhood' (Kitwood and Bredin 1992: 271) and undertaken willingly by carers (Keady and Nolan 2003) in a way that includes self-sacrifice (Shim et al. 2012). As most carers were women, and people with dementia at times described as 'like children', this necessarily calls for a discussion of gendered notions of care and work. While a full discussion is beyond the scope

of this chapter, I briefly consider feminist framings of personhood (Bowden 1997; Sherwin, Held 1993) and Strathern's research with English mothers' relationships with unborn fetuses and ultrasounds (1992). I consider this body of work to gain a deeper insight into how externalised documents can inform women's responsibilities as carers, why the home and intimacy featured so prominently in ideas of what 'counted as care' in future imaginings, and underpin my suggestion that carers' efforts to navigate bureaucracy on behalf of their family's future is 'hidden work'.

In this chapter, I first describe how carers and people with dementia spoke about, or rather did not speak about, the future. I demonstrate that the hesitancy with which they detailed any specifics about their long-term future contrasts with how they discussed their pasts and presents. I then examine a topic that my informants *were* specific and adamant about – the importance of a person with dementia staying in their home. Next, I explore the legal and bureaucratic paperwork processes they pursued, or 'sorted', to show that these processes allowed my interlocutors to feel that the future was safeguarded, without needing to detail specific plans. In outlining which documents they spoke about most frequently, I argue that paperwork came to be seen as a way to express a person with dementia's wishes and decisions in the present, before a future in which a person

with dementia is no longer able to make decisions arrives. I also describe how 'getting it all sorted' became a timeline upon which people mapped themselves, in ways akin to the dementia progression timeline discussions explored in previous chapters. I link this to questions that arose among carers about a person with dementia's ability to have 'capacity' to make decisions in the future, and the role which capacity played in people's perspective on their person with dementia's independence and reliance on others in their family. In the final section, I explore how bureaucratic processes of 'getting paperwork sorted' highlight and remould the dynamics of families' relationships. I explore dynamics that arise amongst family members, between carers and people with dementia, carers and the state, as well as those influenced by one's gender. Across these discussions, I draw out the ways in which the moral underpinning of care, kinship and personhood are at stake in significant ways.

### **'What will come will come...': Being vague about future plans**

A few months into attending support groups, Caring Cafés, and other socially-oriented activities organised by the Alzheimer's Society, I found a pervasive hesitancy to discuss the future amongst carers and people with dementia. This hesitancy was subtle, as exemplified in my conversation with Helene and Leopold.

Its ubiquity became apparent as I felt increasingly uncomfortable asking specific questions about the future in casual conversation and that I had mis-stepped when I did. In response to my questions, both carers and people with dementia alike would only mention what they 'usually' did, or segue, with varying finesse, into a different subject. Many of my interlocutors avoided envisioning or planning the future with any great or permanent detail, often saying that 'what will come, will come'. In support groups, members often made comments such as, 'You just don't know what's coming, do you?' and 'it's best not to plan too much, dear', with some explaining that 'I try not to think about it [the future]'. In an interview with a carer, I asked about what he and his sister thought about how they would like to handle his mother's growing care needs. He responded with 'I just don't know' and after a pause, went on to say,

Perhaps she would move in with my sister?...That seems like it could work, haven't asked her!...Frightening thought really, that we haven't figured this out...but, it's hard to even know [what to plan for]. Mum's also not wanting to talk about it, so I suppose Sheila [his sister] doesn't want to push, yet.

In another interview, a woman whose husband had recently been diagnosed with Alzheimer's, explained to me that,

I don't think he's read anything about it [his diagnosis], I think he [husband with dementia] has an idea what the future might hold but he doesn't...doesn't want to know. And honestly, I can see why, so...I don't push.

Perhaps an obvious, but salient, point is that when carers and people with dementia spoke about the future, there was an inherent assumption that the future most likely meant that 'things will be worse'. Avoidance of thinking about the future of one's dementia progression or caring tasks was cast as inherently natural because, 'Can you blame us? It isn't as though you're daydreaming about a holiday, is it?'

So, if carers avoided the topic of the future directly, what then informed their oblique discussions?

For carers, 'the future' was only vaguely informed by medical prognoses of different types of dementia given to them by 'experts' – GPs, neurologists, psychiatrists, books or information found online. Whereas previous chapters have described carer support groups' concerted constructions of lay diagnosis categories to understand the present, carers made much broader references to

'what might happen' or 'be coming'. These speculations about the future were in part informed by what other carers who were 'farther along' had experienced. Long-standing carers' stories were dubbed as a helpful underpinning of the group's purpose, exemplified in one carer's comment that 'this group's good for that – lets you hear what might happen...so you can prepare'. Here, it was in the sharing of social knowledge and experience that the specificity of possible futures came into focus. There were speculations such as 'it'll be harder for him to talk, most likely, especially if he spends so much time alone' and 'I can see the (toilet) accidents becoming a problem – she had two last month, and I don't see it getting better'. Carers also made comments such as 'you won't always be able to leave him on his own', which at times led to uncomfortable contemplations of 'needing a care home' and underlining that *what* might happen was not entirely knowable, but also *where* people might be in the future. Only on rare occasions did carers make more specific statements of likely events, such as 'the GP says she thinks he might start losing vocabulary soon'. When contemplating a particularly dire set of circumstances experienced by someone else as one's own future, they were cast as 'possibilities' and that 'really, you can't know for sure' and that 'nothing can really be planned 100%' in both the progression of dementia and a carer's future care responsibilities.



While these speculations were, in part, based on other people's experiences, carers were also careful to reference a person with dementia's unique personality and history. In support groups, carers noted that the variance between people with dementia meant that 'there's no way to know exactly what's going to happen' and 'you just can't predict for sure just because someone else's husband went a certain way'. This notion was also touched on in CRiSP, the carer's information workshop run by the Alzheimer's Society. There it was explained that 'each person [with dementia] is unique, so therefore their dementia and its progression is going to be unique too.' Thus, the future was a complex calculation, in which the biology of dementia and its progression was a factor, but one that was not well understood, and which was affected by other variables such as personality and circumstances.

In groups for people with dementia, the future was also considered and referenced in vague terms, such as 'well, that's not here yet' and 'I don't think it does much good to dwell on it [the future]'. In interviews, I would gently ask about future plans and was often met with uncomfortable silences, a grin and a shrug, or comments such as 'I've thought about it a bit, of course, what I'd like, but haven't...decided, there's time' and, 'Well, I've talked with my brother's children – I don't have any myself – about all the legal side of it, my niece will have power of

attorney, I think, I've decided, but we haven't got it sorted yet. I'm fine on my own for now'. In such comments as these, the vagueness of the future was coupled with an indeterminacy regarding which future situation might arrive, or when, making time unformed and elastic and, as such, protective against 'needing to decide now'. Significantly, decision-making and planning for the future were coupled together and also referenced 'speaking with kin', underlining that future planning was not a straightforwardly autonomous activity.

In other cases, the lack of specifics and details about the future also highlighted memory issues, directly and more subtly: 'Oh I know I've put some things in place, but [chuckles] I can't remember what exactly!' Or 'I...I talked to my son about what I want done...with the house? Oh well, he knows, you can ask him.' Here, avoidance of discussing the future might be a strategy aided by memory loss, in which vagueness about the future may or may not be deliberate. These memory challenges also made contemplations of the future uncomfortable and 'blank', a word used by a woman with dementia during an interview. Contemplating the future caused discomfort similar to forgetting past events. Memory issues excused talking about specific plans made for the future. Thus, the future also complicates standard ideas about the temporal range under the jurisdiction of memory. I

suggest that memory is not only a recollection of that which has happened, but also of futures planned and imagined.

In the previous chapter I showed that people construct who they are, based on who they 'have always been' and what they have done and do currently. I suggest that people also construct who they are, based on who they will become. In being vague about the future, people with dementia protected historical constructions of their selves by declining to pinpoint when such 'changes' in their circumstances, activities or personalities might happen. This reinforces and challenges the necessity of temporal continuity in identity making through tacit acknowledgement that 'things are going to change' or 'I'm going to get worse' but not detailing what change this might be or when it is likely to occur. In this way, the continuity of the self is envisioned as carrying forward, uninterrupted by illness. This relates to Bury's 'biographical disruption' (1982), but reaches beyond his focus on narrative of the present and past as source material for the construction of identity and that which disturbs it. Even in the midst of making more specific decisions about future eventualities, my findings show that they were often framed as in keeping with their past and present selves.

Interestingly, people with dementia were often more vocal about their worries about the serious implications of a recent cancer diagnosis, diminishing eyesight, progressive arthritis or complications from diabetes, than direct discussion of their possible and probable cognitive/memory decline. These other illnesses were cast as normal eventualities 'that happen as you get older', subtly signalling their own futures as mirroring 'normal' old age. This links to Kaufman's findings that old age, among North Americans, is often seen to 'start' with the onset of illness in the later years, rather than a particular age (Kaufman 1986). Indeed, these illnesses, in the context of dementia, seemed to offer less of a 'biographical disruption' than cognitive decline. In excluding dementia, they also made a subtle division between normal ageing and dementia, underlining the uneasy and uneven ways that my interlocutors sought to normalise dementia, explored in Chapter 2. However, I suggest that the main crux of the problems associated with the complications of dementia or other illnesses rested on the complications they might pose to 'getting on, on my own'. In this, the blur between dementia and other progressive illnesses intensifies because what is problematic about these diseases – their threats to people's autonomy and ability to remain in their own home – merge into the same concern.

One support group meeting for people with dementia brought the topic of the future to the fore in a way I did not witness in any of the meetings I attended. At this meeting, a clinical trial coordinator (CRC) from a large London hospital and memory clinic made a presentation about the dementia drug trials her clinic was currently running and recruiting for. Her presentation lasted about 20 minutes, and were followed by only a few comments from group members, which centred on 'thank yous' and a question about 'how to get there.' After she left, the group discussed aspects of the trials she presented and Heidi, the Alzheimer's Society staff member, asked me if I would be willing to speak about my own experience working as a CRC at UCLA in California. This was one rare occasion in my time spent in support groups when I was asked to speak, or that I spoke, once meetings had officially begun. A man asked me, 'Really, it's [participation in a drug trial] for the future, isn't it?' I responded, 'Yes, but unfortunately most likely these trials won't halt or reverse dementia, but there's always the hope that they might.' Speaking about a few of the drugs being investigated that I had had direct experience with, and which the London CRC had also referenced, I explained that: 'They target particular things called tau or amyloid plaques that are associated with dementia, but scientists aren't entirely sure of their connection to dementia, or if they're just a by-product. So, these trials aren't only about curing the disease but also trying to find out more about it' (for more information, see Lock 2013).

A few nodded along to my description and a woman sitting to the man's right responded, 'Right, so if you do it, it wouldn't be for yourself. I don't think they'd help any of us, but they would help future generations – our grandchildren – from getting it [dementia].' Some responded with approving comments such as, 'Well, that's something, isn't it?' and asked me what was usually involved in enrolling. I explained that each drug trial is unique, with different selection criteria, trial lengths and schedules, however, they usually involved '...a good number of visits over the course of two years. Some might be weeks or months apart but it's important to go to all of them so they can make sure you're doing OK on the medication and so they can keep their data up to date and accurate.' Some look perturbed at this description and mentioned 'what a lot of work it sounds like'. Another woman tutted and said, 'don't know what they're doing - just trying to make money', underlining a subtle suspicion of pharmaceutical medicines and industry, and hopes for a 'magic bullet' in the future, voiced by many others in my fieldsite as well.

In these varying responses, a number of concerns come to light. Group members considered their futures through a social lens, and how their actions might affect those with whom they were connected. They highlighted the significance of

protecting future generations by naming kin specifically. They also expressed disapproval of the hassle a drug trial might create for themselves and others because most trials also required a named care partner. In other conversations about the future, in general, my interlocutors' spoke about current events and recent new stories. They pondered 'what the world was coming to', and traded speculations about upcoming elections, 'what the world was going to be like when we're all owned by China', and localised events happening in the community and within in their families. In these conversations, my informants positioned themselves as socially embedded subjects with a stake in a progressive future, who 'kept up with the times.' In support group conversations we see that my informants with dementia were concerned with mitigating dependence on others in the future, by wanting to avoid hassle created on their account, or being seen as 'out of touch.'

*...but 'I want to stay at home': being specific about future place*

In unpicking how my interlocutors with dementia engaged with the future in ways that obscured the effects of dementia to establish themselves as social beings, it is also important to examine how they planned to remain socially embedded in their futures. Many were adamant about not wanting to become 'a vegetable in a

nursing home' who 'doesn't know what's happening around them'. Indeed, the clearest and most direct intentions carers and people with dementia alike made about the future was their desire to 'stay in my home' or 'keep him/her at home'. Amidst the vagueness of not being 'sure of what's going to happen', most carers and people with dementia alike were resolute that this was 'what's best', despite encroaching cognitive or physical decline. Carers spoke about ways to 'keep him at home' in groups fairly often, highlighting that you 'have to be flexible', and if you can, 'plan ahead as much as possible.' Continuing Care (a service in which nursing care staff regularly come to the home) would often be sought for people recognised to be 'in the final stages' or those who needed specialist care whilst recovering at home after being hospitalised. This service was understood to be extremely difficult to arrange and 'get from the council', and required not only careful navigation of the bureaucracy involved, but fairly unusual health circumstances. It was rarely awarded, and many carers were left to 'manage on my own' to ensure that people remained at home into the latest stages of dementia, or their death.

Despite the difficulty of these endeavours, many carers felt judged at not having 'done all that was possible' or successfully navigating the confusing, complex and drawn-out bureaucratic process to 'keep him home'. Some carers who had moved



their spouse or parent into nursing care told me that they felt judged by other carers. I noticed their discomfort, and at times resentment, during other carers' descriptions of efforts to keep their person with dementia at home 'against all odds', or looked after by Continuing Care. After one meeting that revolved around this topic, a few carers came to me afterwards while I was packing up my things to tell me 'why John's in care' and 'why there wasn't another choice.' I was slightly taken aback when I realised how serious a breach they felt their choices were according to the ethos of group, made evident by their feeling that it was necessary to explain themselves and their choices in this regard to me, and for '[my] notes.' Among carers, the site of care was often a morally charged topic.

Many people were also so adamant on this point that, in interviews, I learned to ask careful questions as to why staying at home was so important. In response, many people with dementia shook their heads or closed their eyes with dread, explaining that '...moving into a place like that [a care home] would really be giving up, wouldn't it?', 'it's just a bit frightening to think...it [the dementia] would be that bad' and 'you're not able to do anything that you want, or when you want, in those places - everything is on someone else's schedule'. For people with dementia, the home becomes a powerful site linked to being in control – of their bodies, their faculties, their space and their time. In contrast, the attributes of the

home, are what carers felt that they lost in trying to meet the needs of a person with dementia in later stages while they still lived at home. As discussed the previous chapter, carers' homes could be made eerie to themselves as their relative's disorientation began to disrupt how and when they occupied different parts of their homes, and left it. Tellingly, a carer whose husband lived in a care home, told me in an almost defiant tone that 'I have to admit that since he's moved, I can do what I want again, more – it's odd that he's not there, but it feels more normal sometimes too.'

While my interlocutors had fairly homogenous, if complicated and uneven, negative feelings associated with people with dementia moving out of their homes into care facilities, sometimes it was inevitable. In these cases, many people with dementia often gave unsolicited explanations about why and how 'it was actually for the best' while acknowledging that it strayed from the 'best case scenario', akin to carers. A few of my informants living with dementia who moved out of their homes during my fieldwork explained their decision to the group and in interviews as 'making the most sense in the long run, considering how things might go – I don't want it get to the point where they [her family] have to worry'. During a discussion about care homes, Karen, a long-standing group member, announced that she would be moving out of London into an assisted living

community near her daughter. She explained that 'the main reason was because I don't have any family left in London, and I'd like to be closer to my daughter and grandchildren. It would be good to be on hand to help.' Various members of the group commended her for courage and foresight, with one commenting that, 'I think it's best to move when you're not stressed – as opposed to under duress – so you can have time to plan, and choose the right place, and get to know people where you're going'.

A fellow member who lived alone commented that he had

read that this is actually the best time to move into a community like the one you're describing – they say they actually want people moving in when they're able to get integrated into the social...social fabric; it's better that way, instead of people moving in when they're just needing care, you know, and can't really be involved.

Others nodded along to this insight and Karen responded with, 'Exactly, so I've decided there's no use in waiting in London – there I'll have my own place, garden and my grandson can come to mine...I think I'd like the countryside more anyhow.'

This discussion, and the places that people with dementia considered as satisfactory alternatives to staying in their home, were carefully presented as

spaces that were not purely sites of care, where one went 'as a vegetable', Instead, they were seen as spaces where they would be socially involved and have command over their space and activities, as opposed to spaces of hospital care wards or nursing homes, which were cast as isolated from friends, family and flow of 'the real world' as well as 'the last stop before death'. As such, they were speaking about *moving home*, not necessarily moving out of their home. Further, this reasoning emphasised their autonomy in making this decision themselves, while also underlining what they would gain in moving, namely closer ties to kin and new social networks.

What also emerges in my people with dementia and carers' commentary is how the spaces of nursing homes are often associated with a lack of control and being 'out of touch', due in part to the fact that their routines and temporalities are tightly governed by their particular cultures and moral worlds (Chaterjee 2006; Gjødsbøl and Svendsen 2017, 2018; Harbers et al. 2002; Kaufman 2003). In the contrasts made between 'staying at home', 'nursing homes', and moving out of their home to spaces that 'were alright', the significance of control over the timing and routines of one's activities emerges. It is cast as paramount to my interlocutors' rendering of what counts as 'home' and a space in which they are not a 'vegetable'. 'Being on someone else's schedule', namely that of nursing staff,

was at the heart of people with dementia's worries about moving out of their home. Recall, for instance, Tabitha's frustration with the fluctuating schedule of the cleaner her son hired in the previous chapter, echoing Buch's (2015) findings that elderly people sought to negotiate the boundaries of their home and help from outside professionals by dictating the timing of when people could and could not enter. While moving in with family was considered a 'good' alternative to being able to stay at home, tellingly, a loss of temporal control also factored into the hesitancy many felt with this option. They cited concern about how they would find having to fit into the established routines of adult children or that they might 'get in the way' and about 'not wanting to be a burden' or an object of care. In contemplating their future living arrangements, people with dementia sought to strike a balance in the tension between 'staying independent' and 'keeping connected'. This fits in with their pervasive avoidance of direct discussion about dementia or relational dynamics that slipped too close to outright dependence.

Carers made similar associations with care facilities, wherein their person with dementia's time became dictated and adherent to the needs of staff caring for many people, as opposed to the flow of familial time. They were troubled by the repercussions on their relationship that spending time out of sync with their person with dementia might pose, because once their person was in a nursing

home, sharing meals or small daily routines became nearly impossible. These worries were also linked to concerns about 'things being done right' with their person with dementia's care. Primary carers and, in particular, spouses, and to a lesser extent, adult children, who lived in the same home as the person they cared for, often remarked that 'I just don't think that anyone can do it as well as I can – no one knows what he likes as well as I do.' In carer groups, intimate and everyday care was seen as best done by kin 'out of love' as opposed to professional carers for whom care was an occupation. Care performed outside the home by unrelated people was cast as also potentially dangerous and harmful to the wellbeing of a person. It was 'important to keep someone at home because otherwise you can't do what needs doing...they could just be left lying there waiting, when the nurses are in charge or the staff somewhere else'. Many spoke about their expertise in caring as rooted in knowing their person with dementia as a person and over time – their idiosyncrasies, habits, routines, preferences – as well as their knowledge of how to 'make it all work' within the familiar space of the family home. As such, the difference between nursing facilities and one's home was not one of mere geographical space, but also of temporal flow and historical, working knowledge.

Comments about the danger of care performed by outsiders allude to a dark side of care. Indeed, carers whose person with dementia had moved to a care home

emphasised their frequent – often daily or more – visits to the care home. Tellingly, they did not explain that these visits were to spend time with their person with dementia, seeming to rest on an understood assumption that this was important, but did denote the ways in which they ‘checked on’ the care being done. They worried that the process of ‘putting’ a person with dementia ‘in a home would actually just make things worse – he’ll get so disorientated, not knowing where I am or where he is’ or become agitated and unmanageable. In living away from the home carers also wondered if their person with dementia would ‘forget quicker than normal – you know what they say about social stimulation? Or triggers for their memory?’, recalling the previous chapter’s discussion of the importance of routine and space in keeping people embedded in family life. In this, we see that care facilities became perceived as sites that also risked relational embeddedness. Knowing kin by knowing what care practices they needed – and continuing to know these into the future – was an important way by which relatedness was made and maintained beyond formal identification of kin (Carsten 2000, 2004; Franklin and McKinnon 2001; Holly 1996). This relates to other work on ‘interpretive caring’ in which ‘wives [of people with Alzheimer’s disease] operationalise their knowledge and understanding of their spouses, the disease process, and themselves in order to maintain *both partners*’ (Perry 2002:310, emphasis added). This can be seen in how many carers, despite

expressing long-standing exhaustion and stress, remarked that they themselves found it difficult to adjust to 'an empty house' and 'the loneliness', and others contemplating outside care remarked, 'I suppose I wouldn't know what to do with myself at first!' In Perry's study and my own, the importance of enacting care for the emotional and relational health of both partners emerges. The range of carers' feelings and experiences from guilt, loss, loneliness, and relief closely mirror other work on the topic of care homes and dementia in Sweden (see Graneheim et al. 2014).

While care homes were seen as a last resort choice for many carers, the importance of breaks or respite 'to be able to manage in the long term' was well understood. Carers' specificity about respite arrangements - 'time off for yourself' 'to rest', contrasted with their avoidance of talking about a future of anticipated, but uncertain caring responsibilities and dementia progression. Carers' celebration and encouragement of respite underlined that their futures would be dominated by care, and the only way 'to make it through' is to 'take breaks when you can'. Many new carers who lived with their family member with dementia had to be convinced by more seasoned carers that respite was necessary 'because if you're sick on your back, how are you going to look after him?' – casting respite as morally 'OK' because self-care in this manner was ultimately in the service of



their person with dementia. They took the tack of helping unsure carers to reconsider the fact that relatives or professional carers 'who might fill in really can take care of him well enough for a little while'. Importantly, these seasoned carers questioned the level of expertise needed to care for a person with dementia 'for the short term', instead of questioning a carer's level of expertise in caring for a person with dementia in their home. In this, the future is cast as an endurance project that requires a marshalling of strength, energy and time *away* from the home, underlining how the home became the site where they worked hard to keep these ongoing care responsibilities centred. Only in leaving the space of the home were carers seen as 'having a chance to get a break; not always be worrying after him'. Also, by approaching unsure carers in this way, carers' attachment and command of their own home and the intimate labour within its boundaries was carefully left unchallenged.

Carers and people with dementia often highlighted that they were the experts in their own homes, and if they sought help, they did so because they understood the problem at hand and how it must be solved. However, problems and solutions that required paperwork were often a different matter. In carers groups, conversations about respite were not only encouraging, but centred on 'how to do it'. In many conversations, respite was understood as something that carer

needs to 'take for yourself – yes, it can be expensive to get a carer in and go away, but *you have to*', and would need to be self-funded or made possible through contributions in time, and possibly money, from kin. In some cases, people explained that funds for respite 'could be awarded from the council – sometimes, but you have to ask for it'. This was cast as a somewhat daunting enterprise, and arranging for 'help' to take respite required help from others, such as Alzheimer's Society staff, to 'sort' the paperwork to 'get away for a bit.' As the next section shows, carers' and people with dementia's feelings about planning for the future through official and bureaucratic documents point to the significance of the domain of these processes as outside the realm of the home.

### *Piles of Paperwork: Keeping decisions safe for the future*

This section concentrates on my group members' discussions of the need for, and their 'sorting' of power of attorney, wills, medical directives and social service paperwork. I show that these processes allowed carers and people with dementia to sidestep describing uncomfortable future possibilities in detail, while 'protecting against things that can happen' to ensure 'safety for the future'. Discussion of legal and official paperwork and its processes was most often the form that support group conversations about the future took.

The link between paperwork and 'thinking about the future' was made clear in many of the Alzheimer's Society handouts distributed in groups and on the Alzheimer's Society website. For example, the webpage 'Planning for the future' (Alzheimer's Society 2017) starts with a section entitled 'Things to think about', which outlines different categories of paperwork such as Lasting Power of Attorney (LPA), Enduring Power of Attorney (EPA), Advance Decision, and Advance Statement. Much of the information found online about these documents was neatly laid out in pamphlets and flyers, with ample use of acronyms and capitalisation. Drawing on Bourdieu's examination of written sources created and kept by the state (1996), I suggest that the style of presentation of 'all this paperwork' textually signifies these documents, and working knowledge of how to complete them, as apart from the everyday and under the jurisdiction of governing bodies or those with legal expertise. It situates decisions for the future as decisions to be made along official pathways to ensure that they are properly safeguarded by, and under the power of, the state, as opposed to through casual conversation or agreements between kin 'that might not hold up if you have to go to court'. Often, these documents seemed to articulate that decisions about how possible future events are to be handled were 'one size fits all'. For these reasons, I suggest that the bureaucratic lens served as a more comfortable

framing of the future for most of my interlocutors because it was both impersonal and communal. In their 'one-size-fits-all' fashion, the processes circumvented the need to contemplate the individual, personal and intimate details of one's future and navigate the process of making these plans and arrangements alone. Instead, it was encouraged to seek assistance from those knowledgeable about these processes, thereby gaining assurance of having followed official avenues such as 'just filling in what the online government form asked'.

It is important to note that Alzheimer's Society staff most often instigated group conversations about legal and bureaucratic paperwork. They passed out handouts that explained these documents to group members, asked members how they 'were getting on' with different paperwork processes and offered help. However, my interlocutors also asked each other direct questions, such as 'Do you have your will sorted yet?', whether they had 'their power of attorney done', or had 'thought about a medical directive' or 'How far along are you with all that?' My informants expressed frustrated confusion about 'what exactly needs doing' in terms of 'paperwork' and, as such, the subject of paperwork was touched on fairly often in support groups. Explanations in handouts often served as the cornerstone of group consensus about 'what they're [different types of bureaucratic processes] about'.

Powers of attorney, often officially referred to as 'lasting power of attorney (LPA)', explained in line with official Alzheimer's Society guidance, is 'a legal tool that gives another adult the legal authority to make certain decisions for someone if they become unable to make them themselves. The person who is given LPA is known as an 'attorney'. They can manage finances, or make decisions relating to a person's health and welfare' ([Alzheimer's Society 2017](#)). Power of attorney was brought up frequently and marked as important by carers and Alzheimer's Society staff alike when it came to discussions of the future and 'what should be sorted first'. This was shortly followed by medical directives, or Advance Directives, which were explained by staff as 'hav[ing] to do with decisions about what the doctors would have to do to keep you alive, really, like if you wanted to go on life support or want extra measures. For example, if you would prefer a DNR (Do Not Resuscitate order), you can put that in.' Many of my interlocutors with dementia indicated that they not want doctors to go to 'any great lengths' or to be 'kept alive to be a vegetable', and often linked these fears that they would, as a result, not 'be able to go home'. In keeping with a general avoidance of speaking about the future specifically, I noted that most discussions about 'what you want done' revolved around measures, referred to in the form of acronyms, which indicated what was *not* to be done.

Power of attorney became a catch-all of official documents. I suggest that this is in part because carers and people with dementia accepted, unevenly and with unease, the inevitability of 'reach[ing] a point where they [people with dementia] are no longer able to make decisions for themselves – this is known as lacking 'mental capacity' ([Alzheimer's Society 2017](#)). Thus, power of attorney was seen as the threshold document that entrusted decision-making power to a relative, and something to be 'sorted' for a future eventuality. People with dementia skirted the topic of capacity more carefully than carers did, but nonetheless, the likely impending event in which a person with dementia would no longer have 'capacity' was spoken about more clearly and directly in power of attorney discussions than in any other discussions I was part of or privy to. Group members proposed hypothetical scenarios related to powers of attorney to test their understanding. People with dementia usually focused on 'when it would be triggered' and carers were most concerned with the extent of one's decision-making power as the attorney in a LPA. For example, Melanie, a woman in a support group for people with dementia asked an Alzheimer's Society staff member,

'If I make my daughter my power of attorney - '

Staff member: [interrupting] 'She would be called just your 'attorney.'

Melanie: 'Right, my attorney, what kinds of things does she decide?

Money and medical things...you can't know exactly why you'd be in hospital, would you? So, what are you meant to decide about what you want done? Or does the decision just go to her then?'

Alzheimer's Society staff were consistent and adamant that these documents fundamentally 'don't give away your right to make decisions', especially when speaking with people with dementia. During an interview with Karen, an Alzheimer's Society support group facilitator, she explained that she makes sure that 'they [carers and people with dementia] know that drawing up your power of attorney and activating your power of attorney are two different things that can happen 20 years apart...so you can fill out a LPA, send it off and then actually wait a few years until you actually hand it over...'

Additionally, I interviewed Sara Wilcox, a woman who had recently started a charity called *Pathways Through Dementia* at the time of my fieldwork in 2015, which 'provides free, accurate legal and financial information to support people

living with dementia'. I asked her about the beginnings of 'families' journey to get all this all sorted.' She explained that often, she had to

do groundwork to explain just what a power of attorney (power of attorney) and the rest even are, really, and that they are in place to protect the wishes of the person who has dementia - they're not just giving away rights to other members in the family to spend Mum's savings how they want!...power of attorneys mark down how that money's meant to spent based on what the person's [Pwd] decided...I urge them to make medical directives too, because you never know what might be around the corner!

In groups for people with dementia, sentiments such as those made by Sarah, which highlighted that paperwork was 'there to make sure [their] wishes' were safeguarded and 'followed through on' was often met with audible positive acknowledgment, 'oh, I see' or 'well, good thing!' Carers responded with nods and similar comments and other such as, 'It does – now that I finally have it sorted – it's good to know what he wants done is decided and written down.'

Such explanations helped to position these documents as representations of future events because in explaining that they did not give away 'rights' *now*, an



implicit *yet* that pointed to an approaching future was made. I suggest that through the lens of bureaucracy, hypothetical and broad future imaginings were made possible because the process of completing a power of attorney did not need 'all the possible things that could happen' to be identified or planned for. Instead, these documents were aimed at one eventuality, that of loss of mental capacity, which was both vague and could not be temporally pinpointed, and medical directives were framed as a measure that prevented unwanted futures often blanketed in impersonal acronyms and jargon. I argue that the primary concern of doing this type of paperwork is the attempt to 'safeguard' the present decisions that a person with dementia might have about their care in case of a future event in which such choices need to be made, but capacity has been lost. By safeguarding these choices and rights, these legal documents in effect safeguarded both a person with dementia's right to assert autonomy in these matters now, and their decisions in the future. Recalling again the significance of decision-making to the making and maintenance of personhood (Lamb 2014), official documents become a place within which this capacity is housed and transferred to keep it alive. Indeed, advance directives were also, at times, referred to as 'Living Wills.' Because the choices and plans made by an independent person with dementia (including who will act as their attorney) as laid down in official documents must be enacted at a later date by someone else, usually their carer

or family member, the concept of independence becomes both temporally suspended and relationally bound. In operating as attorneys, carers, in effect, enact independence for their person with dementia, when this person is no longer able to do so themselves in legally recognisable ways or unable to reliably make sound choices to ensure the safety of their bodies, possessions and finances. Thus, the independence that is seemingly lost in later stages of dementia is resurrected in different and novel ways.

Some carers had to contend with complicated circumstances with regard to capacity and LPA. While discussions about power of attorney and medical directives commonly raised the subject of capacity, or lack thereof, as a future event, many carers were caring for someone who has been determined to have already lost capacity. A few of these carers did not yet have power of attorney or other documents in place and were faced with the challenge of trying to put these measures in place 'by going through the courts' and without the explicit permission from their family member with dementia. These two factors made the process to secure power of attorney from someone in the family extraordinarily more difficult and involved having to fight for this responsibility, 'like they make you feel like you're fighting to take something away from him.' Some of these

carers regretted having no assurance that the LPA was in line with the wishes of their person with dementia at the time 'when he still could have decided.'

*'Getting it all sorted': adventures in bureaucratic hassle*

Most carers and people with dementia who lived alone had to contend with bureaucracy to 'sort' things like registering as a carer within the borough, qualifying for carers' allowance and council tax waivers, requesting a support need and carers' assessments, continuing care, and registering for care services. So far, I have focused on legal documents themselves, but attention must also be paid to the bureaucratic processes by which such documents became 'sorted'. In exploring what this entailed and my informants' investment in completing these processes, we can understand how these documents were positioned as useful in ensuring the integrity of their lives in the future. While it was clear that carers and people with dementia understood the importance of official documents, 'getting them sorted' was another matter and always treated with wariness.

From interviews and group conversations, I learned that a few couples had their power of attorneys in place years previously, before any diagnosis of dementia was made. By majority, these were couples that did not have children, and were

financially well-off. This however, contrasts to the fact that tackling paperwork of this nature seems to be the first time that many families and carers were aware that laying down wishes and choices for the future could be done in these types of terms. Many made comments like, 'I had no idea there was all this to do!' In support groups, carers collaboratively compared and contrasted methods to figure out what 'actually works' because many felt persistent exasperation because 'everything is confusing'. There was rarely consensus, typified in comments such as, 'Well, who knows what's best, really?' and 'It is a bit of a mystery, isn't it! What worked for Edith didn't work for me!' They were irritated that 'social services, NHS, GP offices, etc...each just offer parts of what's needed!' but cannot be consolidated to form a complete and reliable care plan for the present or the future – a finding well substantiated in research on UK health and social care systems (Bright et al. 2013; Manthorpe 2013; Pickard et al. 2016). Indeed, most of the discussions were about how to minimise the 'hassle' of 'how much work it is to sort it all' and confusion of these processes.

In sharing stories about this 'ongoing hassle' and 'what I've managed', people with dementia and carers constructed narratives of successful bureaucratic navigation that revolved around people who had been helpful. Success was often tied to help and advice received from charity professionals who were seen to have

expertise about social services paperwork processes, and the willingness to help with the repeated calls to council offices, GPs, mobility services etc. on behalf of their clients that were required to 'get something sorted'. Indeed, members frequently recommended particular charity staffers, with explanations such as, 'You have to call Nicky – she's the one who knows all about the carer's assessment – it's too hard to figure all out on your own, so you've got to have her to help you. And she helped with calling them [the council] to make sure they actually sent someone out [to the home to do the assessment].'

Indeed, carer's pronouncements link to Sarah Wilcox's inspiration for starting her charity, which was grounded in her experience witnessing 'families struggle and confusion with the legal side of things' alongside caring for a person with dementia. She explained that her primary task was to help families navigate the myriad decisions 'they have to make when organising care' now and in the future. She explained that a large part of her work often entailed explaining what a power of attorney or medical directives were because

it really can be such a complex process – it's not that every family who comes in is going to need the same sort of plan. Some families come in and say 'ok, right, let's put Dad's name on there so he can look after Mum,' but people's situations are different so what kind of legal

documents they need to say what, changes. I help them start to figure that out.

Sarah thinks that what is needed is a bespoke service to address not only families' confusion but their varied personal circumstances. For example, Sarah described a client from a close-knit family whose grandmother had dementia. She told me,

The mum [the client] did grandmother's finances for years, but then thought they should do a power of attorney, to make it official – so there wouldn't be any trouble. She thought that she had to contact her estranged sister...then the sister kicks up a fuss about where's the money going?– so now the mum is sending bank statements to the estranged sister because she didn't know if she needed to or not to be able to get an official power of attorney for her mother's finances set up!...but the family didn't know that that's not necessary, she doesn't need to contact everyone in the family...but when money is involved all sorts of people pop up.

Sara's anecdote positions paperwork confusion as resulting from carers' attempts to fit their family's personal experiences to the framework of standardized types

of paperwork. This complicates earlier findings illustrating how 'paperwork' was treated and spoken about in support groups as a 'one-size-fits-all' article.

It is important to note that while conversations about paperwork processes were discussed frequently and in detail and considered necessary and important for security in the future, they often did not describe actual future plans, in accord with the pervasive vagueness of my interlocutors' approach to the topic of the future generally. Indeed, their details were apparently quickly forgotten and rarely, if ever, explicitly revealed. I often heard commentary such as, 'Oh [laughs], I can't remember exactly what we put down in it', 'It was sensible – took the advice of the solicitor, really', or 'We just chose the standard...I think he put in that our sons would share it [power of attorney nomination]...' Here we see that it was the bureaucratic process that became the focus – not the minutiae of future plans, imaginings, or decisions about 'what to do'.

The importance of tailoring also touches on the new bureaucratic processes created by the Care Act 2014, which was passed during my time in the field. It promised support to unpaid carers based on a carer needs assessment by the local authority. There was great initial anticipation and optimism about the plethora of services, funding and help for carers that it would provide, but

assessments were slow to be scheduled and the questionnaire proved to be confusing and awkward for many carers. Staff and some carers warned that 'your support needs or everything you do won't be captured' without an understanding of how to answer the assessment in the right way. Carers were most motivated to have assessments done when they were trying to secure additional help to care for their person with dementia so that a carer could go into hospital themselves or have a period of respite to avert burnout. For many, the language used by social services rendering their daily lives was unfamiliar.

Carers described the significance of experts, particularly Alzheimer's Society staff and social service workers recommended by word of mouth, in helping to translate their lives into 'what counted as care' in assessments. For example, a carer commented:

I had no idea how much I was actually doing! I was thinking, OK, I spend a few hours a day helping him wash and eat, and taking him to the day centre on Wednesdays, but then she asks me – "OK, are you also staying with him at home to make sure he's not getting into trouble?" (Which I am.) And "are you doing all the cooking and cleaning for him as well? Staying up nights?" She had me tally all that up and it's more



than full-time hours! I hadn't thought that those other things counted, for the assessment.

Carers did not consider the time and effort that they put in to understand, track down, organise and complete the extent of legal and social services paperwork as care work. Navigating paperwork was hard work, but was rarely compared to the work many carers found themselves doing for their person with dementia daily, such as cooking, feeding, washing, supervising etc. These activities did seem to 'count' as care work in their reckoning of the term and were what carer's assessments and needs assessments centred on most. Bureaucratic hassle was not accounted for in official assessments, but can be cast as 'hidden work'. Many carers commented that their kin with dementia 'has no idea how much time I spend trying to get it all sorted'. Further, it was performed mostly with strangers, not their person with dementia. In stories about doing this work, carers do not mention appreciation from their person with dementia for their efforts, in contrast to the way in which their person with dementia's appreciation would be quietly mentioned when carers talked about the intimate, daily caring they provided. I suggest that this lack of appreciation is part of what made paperwork so maddening and draining for carers and why these efforts were not counted as care work. This links discussions in previous chapters of the significance of

acknowledgement and reciprocity of care in perceptions of, and constructions of, relatedness and kinship (Taylor 2008). Here, I push this further to suggest that the reciprocity and acknowledgment of care is what makes certain actions 'count as care', to use the language of my interlocutors. This lack of acknowledgment is perhaps complicated by the fact that 'hassle' pertains to public domains and is undertaken by carers away from the private spaces shared with kin. Its visibility is thus obscured by both its lack of intimacy and the fact that the scope and processes of bureaucracy is only truly understood once one 'actually tries to get it sorted'.

In enlisting 'experts', carers and people with dementia were effectively asking for help interpreting their situation into 'services' language- an 'expert' language that stood in contrast to support group discussions about members' expertise and command over other, intimate aspects of their lives. This redefined realms of expertise in this context in particular ways: expert knowledge about processes and content of legal and social service bureaucracy was held by Alzheimer's Society staff, and expertise and success were crafted by carers (and, to a less pronounced degree, by people with dementia) by building knowledge and a network of people from whom to ask for help. While I have concentrated on ways in which carers were successfully assessed, it is important to highlight that many were never able

to reach the point of assessment because of prolonged waiting times due to understaffed council offices, and the frustrating 'back-and-forth' of bureaucratic paperwork. For this reason, the Care Act 2014, as a whole, was most often described with exasperation and as a 'failure to launch' initiative, and many carers fell back on the expertise of the group to 'figure out how to manage.'

Paperwork was also used by group members to map one another on a dementia progression timeline to determine 'how far along' a person with dementia was. Carers and people with dementia decisively questioned one another about what kinds of documents they were aware of, and 'had sorted'. More seasoned members would advise new members about what they 'need to do first to plan ahead – it's best to start now before it gets harder...later'.

In addition to asking about the status of power of attorney, carers frequently checked on the status of 'carer's assessment' and 'care needs assessment' paperwork and appointments to map one another's and their own 'progress' on a timeline specific to the future, centred on preparation. If a new member of the group shook their head 'no' in answer to questions about starting these processes, or answered 'What's that?', audible tutting and comments such as 'You've got to have that done!' were heard around the group. 'Checking up on' each other was

ongoing work. When a carer whom everyone knew was struggling in regard to paperwork, other carers at the meeting almost always asked, 'How are you coming along with all the assessments and paperwork?' Notably, carers most often asked questions about who was named as the attorney and the hours and duties tallied as part of a carer's assessment. How actively and in which realms of a person with dementia's life a fellow carer was making decisions, as well as how much responsibility a carer had to take on in response to their person with dementia's diminished ability to independently manage their own affairs on their own, became important in charting dementia and dependency progression as measured by whether or not he/she 'still had capacity' or needed an 'attorney'. Carers could perceive the disease progression, and also the future, and impending landscapes of people's relationships.

### **Changing informal relations through formal paperwork**

In this section, I examine the relational consequences of perceptions that people with dementia will at some point lose capacity, and of bureaucratic paperwork processes. I explore the relationships between family members of a person with dementia, those between people with dementia and carers, and finally, perceptions of the state held by the people with whom I worked. Tensions created

by how the responsibility of care is conferred, fulfilled or neglected run throughout these relationships, and highlight that care is taken seriously by my informants as a high-stakes negotiation of independence and dependence, as well as relatedness. They also reveal that 'how things should go' in the future is a contested issue.

*Relatives are 'always kicking up a fuss'*

Who was named as attorney for a person with dementia's affairs could create rife familial conflict. Although usually only one member of the family was named in a power of attorney document, this decision was, at times, contested by other members of the family. Riona, a woman whose father has Alzheimer's, told me about her experience being her father's attorney:

It's been awful, Lilian, really it has – Dad named me power of attorney over all the money things ages ago, before my mum died, and now that he can't really do it for himself, I've got full run of his accounts to pay all his bills and for the house, and the carer that comes four days a week. But my brother and sister are always on about how they want his money spent on other things – that I'm spending too much on his carer,

they know they could find cheaper ones – but Lilian, I’ve tried the cheaper ones and Dad hated it, always stuck at home and now we’ve got Wallace, a sweet, young black man, who gets on really well with Dad. He takes him out to his favourite places – they play billiards; it works so well with him. And I say to them, ‘Look it’s Dad’s money and he deserves to have the carer that he gets on with, and who I know I can trust; you know Dad wanted to stay at home,’ and they come back saying that I’m probably using some of Dad’s money for my own things, and that I’ve got no right to just spend it without checking with them first. And it’s terrible, really, it’s been bad enough that I can’t sleep sometimes and so I ask our accountant who we’ve had for ages, and I ask him, ‘Am I doing this right? Should I be talking with them about what I think needs doing?’ And he goes to me, ‘Riona, *yes*, you are doing this right, we have it all written down here, we can see that every bit of your Dad’s money is going to his things, I’ve got it all down and, Riona, *it’s down to your decision – you’re the attorney.*

Riona’s story illustrates that, while in the abstract, a document giving power of attorney is ‘official’ and clearly stipulates who holds which kinds of responsibilities presently, or will in the future, this did not always play out the same way in familial

life. The meaning of power of attorney in carers' groups, among carers, does not evenly translate to the understandings of other people in carers' lives beyond these groups: 'I tried to tell her what a power of attorney is, but she didn't...I'll have to bring her a handout,' one carer said when speaking about 'organising Mum's things' with her sister. Many felt they were treated as though they had 'stolen something from Dad'. Thus, 'having a power of attorney' does not count as the final word for everyone who might have a stake in the proceedings of a person with dementia's life. Here, the importance of carers' collective conversations and Alzheimer's Society staff education about powers of attorney in creating a coalesced meaning and understanding of the boundaries of this document emerges. The public, 'official', 'one-size-fits-all' document does not reflect the unique terrains of responsibility and power within families.

I also heard from many carers with familial tensions like Riona's who felt that their families undermined their status as attorney by questioning whether the carer-attorney was 'really doing things the way he [a person with dementia] would have wanted'. Different family members held differing ideas about the importance of ensuring that people with dementia's decisions were supported or enacted. Carers, who often called themselves 'closest' to their relative with dementia, explained that they best 'knew what he would have wanted' and felt compelled

to make decisions based on the desires of a person with dementia, not on the opinions of other family members who sometimes 'only see her once a year!' and 'don't know what's really going on.' For many carers, the responsibility of 'being power of attorney' encompassed not only making decisions on behalf of their person with dementia, but determining *which decisions* to make that were 'right' and 'what he would have wanted.' At times, this has to be done against the backdrop of familial worries and complaints that 'there goes everyone's inheritance' when expensive in-home or residential care was selected. Other narratives featured other family members' wishes 'to just keep him safe – no matter what' even if this meant keeping someone inside or watched at all time – a contentious issues for close family carers, as illustrated in the previous chapter.

Who had the right to make decisions about 'how much independence he should still have', whether a person with dementia can still 'be left alone without someone', and the fate of their material possessions was, in many cases, a frustrating, stressful and confusing subject for carers. What emerges that is that carers who held power of attorney rationalised the 'rightness' of their holding this responsibility based on 'being closer' to their person with dementia than others. This was tied to their working knowledge accumulated as a carer, *knowing* what was needed now, but also how to determine what might be needed in the future



as their person with dementia changed. For example, Inna, a woman whose husband had dementia told me,

My children want to take it over [handling the finances and decisions over their father's care] because they think it's too much for me – but they don't seem him that often. He can't speak very well anymore, but I can understand him – they wouldn't know what he means. They would just decide things based on how they think it *should* be, rather than what will keep him calm.

Stories like Riona's and others described were often shared in carer support groups as counsel to carers who were 'earlier' and had not yet arranged for legal documents. The stories underline how the hassle, frustration and ambiguity of bureaucratic paperwork processes might come to pervade their family relationships, and how the powers granted by documentation might need to be constantly defended. The overarching warning for the future in almost all respects was that 'things will change', relationships included.

*Carers and people with dementia*

Arranging to have a power of attorney drawn up and made official, which required the full knowledge and consent of a person with dementia (unless 'going through the courts'), often created a blunt set of circumstances and moments in the relationship between person with dementia and carer. Spouses, especially, explained that 'after coming along to a few of these [carer groups] I knew I should probably have this [the power of attorney] sorted by now'. Some carers explained that they had had 'little talks' about this topic before, but only a few said that they had 'come to a conclusion on the matter' before attending a support group. Many acknowledged the need to discuss their partner's dementia with their partner to think through how their future together might progress, however no one relished the prospect of this conversation.

Some carers ran into resistance from their relative with dementia, explaining that their partner or parent did not want to 'sign away control' or 'give up their independence' but carers were worried that this would 'leave us in a mess!' Seasoned carers advised that they had 'started the conversation about it saying 'we had to talk about general family plans...and that having this done would make it easier for everyone...a good idea for the whole family'. This echoes perspectives held by people with dementia who were 'easy' about the power of attorney. Stories of 'doing it together', in which both spouses made each other their power

of attorney, 'worked – but of course if it came to it, it would go to my daughter because they'd see his diagnosis'. This advice, while presented as a mild 'trick' to 'bring him around to the idea', nonetheless fixes power of attorney documents to the organisation of family life as whole, not just as it pertains to the future or autonomy of the person with dementia. In this, carers sought and created ways for people with dementia to 'care back' and 'take care' of their families, thereby loosening the hold of the carer/cared for dichotomy, and framing 'giving up some control' as the result of a person with dementia's own decision to do so.

To think through the relational ramifications of these documents, I draw on Strathern's work with English mothers. She argued that the attachment instigated by ultrasound images positioned mothers to become a person with whom a child can bond and to create emotional environments to 'cue' this bonding (1992: 49). I suggest that power of attorney and medical directive documents instigated my interlocutors' tactics in similar ways. My interlocutors' approaches to these conversations can be seen as carefully prepared 'cues' for people with dementia so as to give them opportunities to agree to legal processes as an act of care for their family, a chance to name the trusting, emotional bond they felt with particular members- or to decide *not* to get paperwork 'sorted' for the best of the whole, as it were. In this, *both* people with dementia and carers had a stake in

shared decision-making, which maintained people with dementia's continued involvement in family life *as well* as their autonomous decision-making, echoing both elements intrinsic to personhood. This analysis also accords with Kitwood's research on dementia care, which has argued that informal carers' actions and treatment of a person with dementia are fundamental to creating conditions supportive of personhood (1997). Kitwood has garnered critique from others concerned about the compounding stress and blame this approach to dementia care can put on carers (Davis 2004), similar to Strathern's observation of the responsibility placed on mothers to create the environments necessary for their child's ability to bond (1992).

Bureaucratic hassle aside, some carers found the process 'surprisingly easy'. They cited 'trust' between partners, or parents and children, as the reason that their person with dementia 'was happy to let me sort it all'. These types of stories were also recounted by people with dementia in their groups through comments such as, 'I've named my son – we're very close and he works in the bank, so I know my money is going to be in good hands [laughs]' or 'my daughter brought it up to me and she's such a help to me and her father...I want her to worry less', recalling discussions in earlier chapters of how many people with dementia often did things primarily for the benefit and peace of mind of family members. When these types

of stories were recounted in groups, carers and people with dementia responded with, 'You're lucky!' and 'that's nice – as it should be,' pointing to the perhaps unnecessarily obvious fact that harmony and trust within families were considered good and right and sought by all my interlocutors when making 'family decisions'.

Importantly, these were contrasted with some of my other informants with dementia's experiences – not everyone has the experience of a rosy family life. Some discussed 'having to be careful' where powers of attorney and medical directives were concerned because of worries about relatives' bad intentions. Recall earlier descriptions of Lucy's (Chapter 2) and Flora's (this Chapter) descriptions of their sons. In describing how her son 'took all the money from the business', Lucy remarked that she was 'so thankful I've got our daughter taking care of things – and I suppose we [she and her late husband] learned earlier rather than later that my son would have taken it all. Maybe it was better he did when he did, rather than when my husband got ill.' Flora, in worries about her son's interest in her moving into a care home, was counselled by an Alzheimer's Staff member not to make him a power of attorney 'because you have to trust the person you choose.'

These anecdotes show that when carers and people with dementia alike first considered the need for these documents, they were not overly concerned with knowing which specific decisions were going to be made about their futures. Instead, it was important that the 'right' trusted person was making them. Akin to the perceptions of carers in the face of familial backlash, many people with dementia explained that it had not bothered them to name close kin – usually a spouse or child – as attorney because this kinsperson 'knew' them and 'what [they] wanted'. In this way, we see that power of attorney in this scenario is less about giving up decisions entirely, and more about trust that wishes will be carried out in line with a known identity and set of values, even if the decision-maker has changed. The ease of decision-making was also linked to the fact that it 'wouldn't be needed for a while', although some said that 'soon after' it was put in place, this child/spouse started taking a more active role in 'deciding things'. In these renditions, against the backdrop of an ambiguous and unknowable future, one's kin could be a reliable mainstay.

However, even 'easy' situations ran the risk of culminating in future stress and uncertainty. Some people with dementia lost insight into their dementia diagnosis and did not want to have a power of attorney activated at a later date. Although an Alzheimer's Society staff member explained that 'all you have to do is convince

an appropriate person that this person hasn't got the capacity to make that decision and then the power of attorney kicks in...' carers found this distressing nonetheless. Many expressed feelings of guilt and sadness about having to ask their person with dementia 'to confront that he's going downhill' and confronting this reality themselves. Akin to safety measures described in previous chapters, people with dementia felt 'infantilised' and 'treated like a child' when events transpired in which their 'rights and freedom to be left alone' or 'decide things' 'were taken away' as memory or disorientation problems escalated. Paperwork processes highlighted how carers also saw themselves as the parental (or perhaps more specifically, maternal, considering that the majority of carers were women) caretakers of their person with dementia. This was an extreme role reversal for the majority of carers who were, usually, the spouse or a parent of a person with dementia. Carers who felt as though 'she's like a baby' or as 'being a parent all over again' were often earmarked as 'far along' and 'in the end stages', and their experience was understood as 'where it's [dementia and caregiving] headed'. Further, this was seen as something that would become worse in the future, and carers felt grief that people with dementia 'aren't really like babies though – they don't learn, so it's not as though you can plan on things you can do with them as they 'grow up''. In conversations like these, dementia progression as a

downward slope, or diminishment was particularly stark, and sometimes framed as a narrative 'with no happy ending.'

Guilt was also tied to discomfort at 'taking away' their loved one's independence. In arranging and activating a power of attorney, carers worried that they 'were deciding that that's it for Dad – [he] spent his whole life putting together his savings and now it's not his, entirely, is it?' This echoes discussions in the previous chapter about carers' guilt at wanting to curtail their person with dementia's activities and movements outside the home, but then wondering if 'he'll still be himself'. While most carers grounded their rationale in holding power of attorney in their working knowledge of care and their relative and dementia, this also, at different times, felt like unstable footing. Their faith in their ability to know vacillated, with many expressing doubts about whether they 'really know what he would have wanted' or wants 'as he gets worse', touching on their uncertainties about whether a person 'is really him' in the later stages of the illness. Many carers do not want to take full control. Instead, they found ways to continue to share in decision-making, 'not going to do anything she doesn't want – she can still tell me of course, even if I've got power of attorney' and some explained that they 'thought sometimes...maybe this is horrible, I'll wait to see if he forgets, and then do what's best and often that works out alright, and I'll know he's safe'.



Here, the importance of control over one's decisions in how carers understood 'independence' emerges, but also dynamics of control that mimicked historical relationships and personalities. Many spousal carers described how 'he always decided the big finance decisions' or that 'she was always stubborn – 'can't just go behind her back now'. Attempting to continue to 'decide together' also made room for 'changes' in a person with dementia to emerge and still be accommodated. Thus power of attorney documents were not straightforward replacements for people with dementia's autonomy, nor did my informants easily take such decisions on board. Instead they created scenarios in which their wishes and independence could be supported and maintained in novel ways that were informed by a desire to maintain continuity in people's relationships and personalities.

### *Carers and the State*

In line with other anthropological research on the topic, relationships between people in my fieldsite, as citizens, and the state are informed by the temporality of bureaucratic processes, and specifically, the temporality of waiting (Auyero 2012; Day 2016; Mathur 2014). I examine how these temporalities of waiting

enervated, and thus illustrated, my informants' relationship to the state, which, I suggest, is one predicated on moral framings of care that seem to reverberate with traces of kinship.

It is significant that my research was among a group of people, mostly British English by birth and current nationality, who strongly associated their identity with a nationalised health care system that boasts the NHS and socialised social care services. Day, in her work on waiting for health care in UK contexts, argues that 'recognition of the care claimed and given...defines a public to which you belong' (Day 2016: 180). I suggest that in strongly identifying with socialised services, my interlocutors positioned themselves as belonging to, identified by, and deserving of, care by these systems. I make the leap from expectations of care from the NHS care and related services to suggesting a moral relationship to the state, as envisioned by my interlocutors, through a consideration of their commentary about the role and responsibilities of the NHS and state to provide care over the course of their lives. 'Early' carers often spoke with confidence about how 'services will help sort things [the increasing needs of a person with dementia]', alongside proud comments that 'I've had the NHS all my life.' Carers, at all points in their journey, often made comments that 'the government really does have a duty to take care of them [people with dementia]', and 'dementia is an illness – it's part

of the NHS's remit – everyone's health is important...has to be looked after.' These expectations of care were further underlined when 'new' carers, over time, began to express confusion that 'nothing was happening' and exasperation: 'But we have the NHS!'. This mirrored more seasoned carers' slightly more subdued resignation that 'dementia has shown' that 'they don't even care about us!'

The parts of my support group fieldnotes in which I rapidly scribbled these conversations are underlined with enthusiasm, and in some places, earmarked with a baffled 'why!?' and 'how are they so sure?', 'why 'owed'?'. My own in-note commentary on these conversations reveals, perhaps, my positionality as an American. The United States does not have a socialised health care system like the UK's National Health Service (NHS) which was designed to be free and accessible to all (NHS 2018). Therefore, my response to my interlocutors' description of the NHS and the state's 'duty' to care for them, as well as many people's trust and pride that their needs would be met, struck me as significant, and indicative of particular values in their relationship to the state.

In considering my interlocutors' comments that they and people with dementia were 'owed' by the NHS through the concept of the moral obligation of care (Faubion 2001), it is possible that carers' beliefs in the the aims and promises of

the NHS, were derived partly in a nationalised identity as British. Some commented that the unpaid care they were performing for their person with dementia was care they were 'doing for the government', which they had 'paid into my whole life' and that they should be given support for doing this care 'for free'. While carers', and to a lesser degree, people with dementia's comments that they 'had paid in my whole life – working, taxes' and hopes for payments from the government might seem to undermine this moral underpinning of care, I suggest that this can be read otherwise. Kinship relations and economic ones are not necessarily oppositional in straightforward ways. If we consider that reciprocation of care is an important element underpinning kinship (Faubion 2001; Pettersen 2011), then my interlocutors' lifelong investment in the economic health of the state can be seen as akin to an act of care that prompts reciprocal support in return. This point is strengthened if one considers other findings, albeit based in work in Botswana, exploring how care also encompasses financial and material resources (not only labour and sentiment), which can contribute to wellbeing or ill-health in others (Livingston 2003, 2005). As discussed by Reece, the ambiguous position which 'contributions' hold between gift and commodity in Tswana families, 'beget further contributions in their turn...giving them a cyclic, continuous temporality and generative potential' that 'adapt the moral framework of exchange to incorporate...collectivity' (Reece, unpublished thesis 2015: 119,

121). Here we see that 'contributions' to and from the state have a potential constitutive power to create bonds. Further, carer's comments that much of the work that they were doing, 'should be done' by the state, likens the care they provided to that which the state could and should provide. Noting the importance they placed on maintaining their relative's relational embeddedness, I suggest that this signals a nod to NHS and state support as more akin to the moral charge of kinship care, than only the moral fulfilment of obligations and debts fulfilled. Indeed, carers worked to establish their family member with dementia as a person in relation to themselves – a participant in the state, and an individual 'owed' something to, and not only as a cared-for appendage to the family unit.

The expectation of reciprocation became most clear in my informant's discussions about extended waits for NHS and social care support. Feelings of betrayal and bitterness often marked carers' discussions about the kinds of care and support they felt they were due. They traded tips on how to navigate the confusing bureaucratic hassle of powers of attorney and medical directives to 'be able to arrange things', 'because they [the state or NHS staff] don't explain anything.' These processes were also frequently altered by new 'promises' [such as those offered by the Care Act 2014], alongside the slow implementation of these new policies due to understaffed local and national teams. At a large forum on the

Care Act 2014, hosted by a university in central London in March 2015, many people in the audience who identified themselves as carers, used the microphone to ask panel members '*when* will we actually see any of this [provisions for stipends and respite to support carers]?' and whether 'everyone gets this – or is up to your local authority?' They highlighted that 'much of this is too little, too late – I'm lucky that I could even come here today – so many carers can't even get out. We deserve better than this.' Some of the more frustrated and disbelieving carers I recognised from support groups, and new contacts I made on the day, commented to me privately that 'I'll believe it when I see it' and 'the NHS, all of it, really is going downhill'. Tellingly, one woman likened the help she'd received from the state thus far to family that just wanted to 'pay lip service.' Carers' frustrated comments signal a debt unpaid, as well as dissatisfaction that the support promised 'won't reach everyone', but instead would differ divisibly between Local Authorities.

Auyero's work illustrates the ways in which waiting for health and social care among the urban poor in Argentina 'appears to be 'in the order of things'—as something normal, expected, inevitable'. Day points out that waiting as an activity in the UK and other Western settings, with 'connotations of a delay endured, and an expectation unfulfilled' is relatively recent and before the early part of this

century, was not associated with queuing (Day 2016: 180). Auyero argues that through waiting 'the *everyday reconstruction of political domination*' (Auyero 2012: 157, emphasis original) is created. He casts waiting as a state tool to regulate the poor that turns citizens into patients and binds them to the state. However, I suggest that experiences of waiting for bureaucratic processes and state services to be implemented in the context of my research actually worked to unbind and distance citizens' perception of being cared for by the state and citizens' embeddedness in socialised health systems. My challenge is similar to Mathur's (2014) research on the slow governmental reaction to a man-eating jaguar plaguing a small Himalayan city. Like her, I suggest that the disjointed, complicated governmental processes and responses to the specific needs of my informants created room for their sharp critique of the state. Among my informants this critique centred on the state's default on promises of care earned. This analysis also reinforces findings on research with cancer patients using UK health services, wherein patient pathways became increasingly complicated by initiatives to introduce 'stratified medicine' approaches, aimed at personalisation and precision (Day et al. 2017). Day et al. showed that the hassle created actually resulted in less personal care. Like her informants, instead of being drawn into a closer, more personal caring relationship with the NHS staff and support services;

my interlocutors seemed to regard the relationship as estranged, often in bitter terms.

I suggest that the aggrieved nature of these critiques signals an affront committed that was personally felt, pointing to an unravelling of a sense of relatedness with the state and a diminishment of membership in the very 'public' created through such services. As such, my material corroborates tensions between care and waiting in Day's findings, which shows 'the tensions within such a public, since participants consider that the NHS belongs to them while, at the same time, they are defined, contained, and put on hold by "the system"' (Day 2016: 180). Thus, we can see that in contemplating their futures, my informants reworked their relationships with the state as they redrafted their perception of the state as a provider of security against uncertain futures.

### *Care and gender*

A discussion of care as it relates to the future merits a consideration of the gendered nature of care in my research context, particularly considering that the majority of carers are women. Due to the confines of this thesis and chapter, this discussion is necessarily brief. I examine how being women affected my



interlocutors' experiences providing care, as well as the dynamics of the relationships outlined above. Their positionality as women informed what they saw as their role in their future, as well as the decisions they made about how to 'do' care in that future. What runs through the tensions in the relationships described above, and other discussions in this chapter, is female carers' marked discomfort at not performing care, or at care being given to their person with dementia 'by a stranger'. This underlines care as a significant aspect of women's responsibility to the family (Able and Nelson 1990), and the importance of relationality to female personhood (Bowden 1997; Sherwin and Held 1993). As such, care outside the home performed by 'others' posed dangers to the personhood of carers and people with dementia alike because it disrupted acts of moral obligation between, and constitutive of, kin.

Historically and currently, women (particularly white women) living in Western contexts are linked with private, domestic spaces, and with unpaid responsibilities managing the welfare of the home and its familial occupants, despite feminist movements of the 1970s (Bowlby et al. 1997; Boys 1990; Hochschild 1989; hooks 1991). A 20 year longitudinal study conducted in the UK with 4339 participants focussing on employment and caregiving histories found that 'persistent' caregivers are likely to be older and female. They also tend to hold these

traditional views on gender roles in care (Carmichael and Ercolani 2016). These views persist even outside of heteronormative framings of 'woman-ness'. Elisabeth Price conducted research with English lesbian and gay male carers, and while this group is not the focus of my research, she found that women were positioned as the archetypal care-giver and that female lesbian carers, and male gay carers to a lesser degree, experienced familial assumptions that they would and could take on caring duties (Price 2011) I found these conceptualisation of the gendered care role particularly salient amongst my older interlocutors, carers and people with dementia alike, as well. Indeed, on a number of unprompted occasions in the field, there were comments made with varying degrees of jokiness such as 'How are you taking care of your boyfriend if you're over here with us [on the weekends] all the time?' and 'Are you going to take a break after you're finished [with my PhD, or fieldwork] to start a family? – don't wait too long!' Considering these ideas about the customary realms, concerns and duties of women, I suggest that the 'public' work of wading through the murky hassle of bureaucracy of carers becomes hidden, or questioned, because it does not easily fit normative reckonings of 'what counts' as women's work and, by extension, care. We saw this in family members' questioning of many carers' decisions as 'attorney', and in a lack of recognition on the part of their kin with dementia. I suggest that, in a reversal of sorts, these public efforts were concealed because

they did not belong to the intimate space of the home. Furthermore, many legal and social services processes culminated in some sort of direct or indirect financial remuneration, either as a stipend to arrange for respite services or power over a person with dementia's finances. Pushing an understanding of women's work/care work as that which must be given, unpaid, and relational to be morally 'good' through its alignment with expectations of women's self-sacrifice and obedience (Okin 1989; Grimshaw 1991; Held 1993, 2000), perhaps this association between paperwork 'hassle' and financial gain muddies the moral waters of this labour, precluding it being considered as *care*.

Notably, all the men I spoke with who attended carers groups and/or Alzheimer's Society services who provided care for a parent, highlighted their financial contribution to the care of their parent and to the support of a female sibling or mother who 'did the day-to-day.' On a number of occasions, Alzheimer's staff members told me that 'most of the people in care homes, or the ones that have round the clock care at home, are the ones whose sons or husbands are having to take the lead on things.' Staff members and my female interlocutors in support groups and interviews explained to me on multiple occasions that 'women just know how to do it - maternal' and

it's like they [men] just don't know how – particularly the older ones – they never had to do any of those kinds of things [take care of babies, children, or the house] so now, when they're faced with it, they struggle. Some can't cope altogether, so they get in help.

In these men and women's comments, as well as the subtle ways in which support groups explained things in more detail to men and made comments such as 'poor thing', we see underlying notions that men do not have the working knowledge of intimate, home-based care that women do. They lack experience, but also because, simply, they are not women. As such, their financial contributions to supporting a family member with dementia did not seem to threaten their own ideas of *caring* for this person, or, often, the views of other family members' view that 'he *is* helping.' This, as one might suspect, was not held by all my interlocutors, particularly women who were lead carers for a parent with dementia.

On a number of occasions, women would comment that their brother was 'getting away with it [their lack of care or involvement] because no one expects him to do anything'. Uneven notions about which gender should provide care, and its ramifications on carer burden was often voiced in complaints such as, 'We've [she and her brother] both got families – two kids each, but it's expected that I take care of mum, sleep over sometimes, because why exactly? A couple of times, when

things have gone pear shaped, my *sister-in-law* came. That says it right there, doesn't it?' While the contrast between the viewpoints between those who appreciated and saw men's financial contributions as 'care' and those who found it lacking is stark, both viewpoints were clear that men usually did not '*know* him [their family member with dementia]' the same way as a female care who 'did the day-to-day' did. While men and their financial contribution could be *caring*, this was not seen to achieve the relatedness which women's informal care did.

I compare carers' hidden work to the energy and effort that Alzheimer's Society staff put into their preparation and ongoing tasks as support staff for their many clients. Staff members spent considerable time and energy helping people to track down and follow up on bureaucratic paperwork. My interlocutors acknowledged this help gratefully in many of my interviews, and often described the staff as 'caring' and 'more helpful than anyone else [in their family] has been.' Work done by staff was acknowledged by carers and people with dementia more than the 'hassle' that they undertook themselves. This may be because staff work was done in public spaces as a paid occupation that those who attended support groups and service settings could 'see' and therefore acknowledge. Tellingly, however, when they were speaking about staff care, carers also highlighted how staff 'went above and beyond' the remit of 'their job' to help. This subtle allusion

to unpaid or voluntary time is important to examinations of how care is constructed, and shows that informal carers' efforts were given different significance from those of paid staff. These considerations matter to contemplations of the future, because they had telling implications for carers' worries of 'all that I'll have to do' as dementia progressed, and as 'more and more organising' of legal and bureaucratic processes became necessary. Although the drain on their time and energy would be mounting, it did not fall evenly on the purview of their role as 'carers'.

## **Conclusion**

While my informants are often uncomfortable with the topic of future, their discomfort reveals what they see as potentially under threat in the forward motion of time, and progression of dementia. A range of themes have emerged, such as independence and autonomy, personhood, biography, kinship, care, the home, and safety and danger. These may seem to be well-trodden ground from previous chapters, and their discussion through the lens of future temporality, redundant. Independence and family relationships have figured strongly in people's sense of self and personhood, and in the stories they tell about their past and present lives. It's also been made clear that the tension between maintaining independence and

staying relationally embedded inform what kinds of dementia management and care strategies my interlocutors assembled. So why then have I gathered together people's conversations – and non-conversations – about their futures? What do we learn by looking through the lens of the future that is different from what we learned from the previous perspectives of present and past?

Firstly, we learn that that the future is a unique temporal experience in the context of dementia care. When people spoke vaguely about their imaginations of the future, if they did at all, an idiomatic turn of phrase from my upbringing in the United States regularly occurred to me: my informants saw their future lives as *in the weeds*. By this I refer to their constant worries about 'being in over one's head' in the future, in terms of care responsibilities or inability to 'sort myself'. The future resisted framing as a forward, linear, well-marked path in my interlocutors' articulations: in being vague about their future, people did not assume they had *no* future, but that dementia frayed their prior plans into an assortment of uncertain, unknowable, and often unfortunate sets of possibilities.

Primarily, I conclude that carers and people with dementia create novel conceptualisations and constructions of personhood through their contemplations of the future, and most significantly through the bureaucratic

processes in which they engage in order to safeguard that future. My informants safeguard a person with dementia's wishes in legal paperwork, in effect preserving the person with dementia's autonomy and 'right to choose' beyond their cognitive ability to do so. Such a construction of independence and autonomy complicates common Western ideas of personhood by showing that the necessity to make personal choices over the chronological course of one's life is met in ways that re-define what 'counts' toward this continuity. The what and when of genuine decision-making are made more complex in my informants' experiences. Even as people with dementia seem to 'become like children' and dependent on the care and decisions of others, plans put in place to 'sort' the future also 'sort' a delayed activation of 'what he wanted'. Further, carers and people with dementia sought consistent return to considerations of people's personal decisions and views, now and in the future, through paperwork. As such, a person with dementia's choice, perhaps delineated in the past, was not static, but one that could be altered as 'things changed'. Thus, people construct a personhood that can be extended into a future of marked cognitive decline by legally safeguarding general and specific decisions about future care.

Powers of attorney and medical directives were put in place in anticipation of the occasion when people with dementia are no longer deemed to have 'mental



capacity' to make their own decisions or those deemed 'safe'. However, it was through *relatives' activation* of these documents' rights, and adherence to their stipulations that these decisions were ultimately enacted and pursued. Carsten has argued that anthropologists, 'in their consideration of personhood in the West...have emphasised the notion of an abstract and legally defined entity, the bounded individual with rights over property and person, as the dominant Western construct. In doing so, they have obscured the most obvious contexts in which relationality as an aspect of personhood is expressed...contexts [which] involve a consideration of kinship' (Carsten 2004: 107). I suggest that my interlocutors' contemplation of and preparations for their future reveal the significant ways in which the making of a person with dementia as a legally defined entity with rights was done through and within contexts rich with relatedness.

As noted earlier, Strathern highlighted the use of ultrasound images of foetuses to bring forward the 'natural' process of attachment and emotional bonding between English mothers and their children to before birth (1992). She argued that 'what is being anticipated is the child as an individual person. It is when persons become visible as individuals that the English feel they 'relate' to one another' (1992: 49). Applying this to the paperwork processes examined in this

chapter, I suggest that documents were sought to explicitly and officially make visible the subjecthood of people with dementia *so that* the intimate relationship and bond between carers and their person with dementia could be safeguarded. The people I worked with did this by abstracting the dynamic of a dependence in these relationships before it became defined by progressive care needs, and by designating a person with dementia's individuality and autonomy in deciding this dynamic. Carers and people with dementia managed their relatedness to others by staking out the boundaries of their separateness and autonomy.

Following on from this, my data has shown Western personhood to be inherently a deeply relational project, underscoring Carsten's gentle critique (2004) of Strathern's foregrounding of individualism in Western personhood (1992). The lives and actions of people in my field site are demonstrative of their relational entwinement with one another, but also demonstrative of *their desire* to be and remain relationally entwined in the future by remaining separate people who can connect to others. This is perhaps why people wished so ardently to remain in their homes, or even consistently and willingly navigate the maze of bureaucracy. People's reluctance to discuss the future was rooted in a discomfort of contemplating a future in which their relatedness to others might dim or change irrevocably. Thus, too blunt a consideration of the future is avoided because

contemplating the future is actually a risk, because 'facing the facts' of 'how things could go' can do violence to a person with dementia's personhood. This is because envisioning, planning for, and clearly articulating futures in which they are 'gone' (but still need care) brings into sharp focus the very state of affairs my informants work hard to mitigate. Contending with the future was an exercise in mitigating and evading the biographical disruption which dementia posed to self and kinship. What emerges is the tenacity with which my interlocutors fought to maintain the integrity of *their* lives *with others*.



## CHAPTER 5: Love in a time of Dementia: crafting connection at Singing for the Brain

Beyond the stone entryway of the old and half-crumbling Christian Community Centre, the room is large, with tall ceilings and scuffed linoleum floors. A line of figures, recently released from the sliding doors of a white van, haltingly cross the room, some leaning against the aid of a cane, aluminium walker or the right angle of a someone's elbow. They hasten ever so slightly at the sight of tea and biscuits laid out on table tops within an undulating circle of 25 chairs. Old join the old.

A large, glass-less window to the kitchen frames two volunteers as they work in tandem to fill tea and coffee orders. Their workstation is a mess of spoons, some wet and half-crusting in sugar, others black with half-melted instant coffee flakes. Carers, people with dementia and volunteers alike come to chat, leaning against the smooth metal platform where the volunteers work. Conversation is a mix of drinks orders, updates on the past week and comments on the weather. I slide between two women discussing their husbands and reach for two white mugs, slightly too full. They move to give me room, revealing tea stained forearms. Before the singing begins, the room is an obstacle course of chairs arranged in haphazard circles, or pushed in stacks against the wall. I navigate through carers and other people with dementia as they mill about, chatting happily. Some sit on

their own, waiting in repose. I place a cup of tea carefully in front of a woman sitting sideways to the table, with her hands resting in her lap. Once my hands are free, she takes them and squeezes them between her own. Hers are warm and soft and a deep brown. She looks directly into my face, placing both her large hands around its circumference, warming my cheeks still cold from my walk to the Centre.

Her fingers reach from my temple to chin and she says in a Jamaican lilt, 'Oh I love you! I love you! God bless you, bless you!'

I smile, enjoying the warmth of her palms on my face, and say, 'Your favourite right, Delia? Tea, milk - no sugar?'

Behind me, a young woman says, 'Delia! I just go to the toilet and you've found someone!' and to me, quietly, 'Has she kissed you yet?'

With a gentle squeeze of Delia's arm, I laugh and say, 'I get a kiss and hug when we say goodbye later, right?' Delia's hands slide down my face as I stand.

I pick up the coffee I'm still meant to deliver and move toward a small group of

people gathered in a cluster. They obscure the form of a man in a wheelchair and, moving closer, I see his hand is held in his wife's. I place my hand on the shoulder of another seated man, saying, 'Special delivery, Bill!' as he tilts his head up at my touch. His eyes are huge behind thick glasses and a mischievous grin crosses his face. He looks across to his daughter, asking, 'Do you think she's got it?', turning then to look at me, a hand cupped over the warmth rising from his cup. Donning a serious face, I report, 'Weak and sweet, Bill! There's more sugar in there than coffee!' Bill cackles and his daughter playfully rolls her eyes. Before I leave, I ask his daughter, 'You're sure you alright?' which she answers with a smile and playful raising of her hands, 'Oh yes- I've had enough coffee today!'

Meanwhile, to my right, another volunteer bends at the waist and leans toward the man in the wheelchair, saying in clear words through a smiling mouth, 'Hello Marcus! Good to see you again! Are you excited to sing today?' Marcus's eyes focus on her face and he opens his mouth wide, revealing every tooth. I move towards him and he turns to look at my face, releasing a loud 'HEEE - AAARRR!' I smile and say, 'Well, hello to you too!' and smooth down the label on his shirt that reads MARCUS in block letters. His lower lip glints with a thin layer of saliva. His wife gently runs a cloth along the strong, set line of his jaw. She looks at us, she looks at him and says, 'You always want to be the centre of attention, don't you?'

and we laugh.

A young woman named Fiona walks purposefully around the room in a wave of friendly bustle. She places her hand on people's shoulders and tips back her head in a chuckle. She gently directs people to move toward the circle and sit. Volunteers follow suit, gently helping people up from their chairs and dragging tables toward the edges of the room. People leave their cups on the tables behind the circle of chairs, and hastily finish half-eaten biscuits. Slowly, they settle in. Some lower themselves into the chairs slowly, reaching out for a helping hand. Others move with grace and speed, hurrying to their favourite part of the room. A group of three men, including Bill, sit next to one another, as they always do, bent together like a cave. I help Marcus's wife manoeuvre his wheelchair between chairs, and she takes her place beside him, returning her hand to his. A fellow volunteer and I then distribute instruments: bells, a small drum, maracas, a wooden frog and small plastic Easter eggs filled with rice. We trade a warm glance of camaraderie as we hold back a small set of drums from the selection to give to a particular carer, the triangle for another, and a stick with bells attached for Marcus. The volunteer holds up a rice-filled egg, shaking it slightly and grinning mischievously before handing it over to me. People sitting in the circle pull blue, well-used folders from under their chairs. Fiona stands in the centre of the circle



of chairs, leaning forward in welcome, slowly spinning like a clock to smile at each face.

In a voice bright and loud she calls, 'Welcome everyone!' and begins the customary 'Hello Song'. Starting with a man in Bill's small group, she grasps his hand and loudly sings, 'HE-llooo GEOFF-rey' and the group and Geoff repeats back "HE-llooo GEOFF-rey" as she and Geoff bounce their handshake in rhythm to the harmony. She moves next to Bill and does the same, drawing out his name into two floating syllables and Bill waves to the group with his free hand. A few people lightly shake their instruments in time to the song, as the undulating rise and fall of the hellos and names of the song fill the room. Minutes pass while Fiona slowly makes her way around the group of about 20 or 25 people. At times, she has to overlap her arms over one another, as some people in the circle continue to hold her hand after she's begun singing the next name. Carers and volunteers gently disengage their hand from Fiona's, sometimes placing it in their own.

Once everyone's name has been sung, Fiona returns to the centre of the circle, and holding up her own blue workbook, instructs, 'Page 25, everyone!' in a voice between singing and shouting. The room fills with wavering tones of 'It's a long,

long way to Tipperary,' that are almost audible above haphazard and enthusiastic percussion. Almost everyone has a folder open across their laps, white pages curved over their knees like conjoined crescent moons. Some read along with the text of the page, and a few carers hold up a folder between them and their person with dementia, a finger tracing the words as they're sung. Carers watch their loved ones with dementia with sideways glances. They look at their faces, concentrating on their mouths, as their fingers trace the words on the page. Many others, chins tilted upwards, sing the words unaided and fluently. Volunteers, myself included, look at people with dementia from across the circle. When they look up, we smile and they smile back. The room fills with a crescendo of the final refrain of 'Tipperary' and the sound of the group swells. A dapper man dressed in layers of tweed stands up, an enormous figure amongst the seated singers. With his arms spread wide, he shouts, 'TRA LA LAAH! WONDERFUL EVERYONE!' We all – people with dementia, carers, Alzheimer's Society volunteers – laugh, and his petite carer half stands, reaching for his hand. He takes it, like an afterthought, and walks around her so she spins, shouting, 'YES, WONDERFUL!' in a voice that booms.

Fiona signals the end of the song with a conductor's gesture of pinched fingers moving away from each other in front of her chest. A man sitting near Bill then shouts, 'Big Spender!' and after a short rustle of pages, the volume of the room

rises again. Everyone claps along as the melody rises alongside jostling shoulders as people imitate Shirley Bassey's 'Good looking, so refined - say, wouldn't you like to know what's going on in my mind?' and hitch their voices for the drawn out crescendo of 'Hey big spender! Spend a little time with me!' Some songbooks slip to the ground, or are closed and set to the side. I look at the woman sitting beside me as she sings the song unaided, I watch her daughter watch her mouth, smiling.

The circle claps and Fiona shouts, 'Page 32!' Semi-melodic voices rise again. Three men with dementia, who sit side by side every week, bounce their feet, and the one at the end slaps his knees in time to 'Pack up your troubles in your old kit bag!' The dapper man stands again, his carer's hand left in a trail behind him as he moves around the young woman and the circle in a marching dance. A volunteer across the room raises her eyebrows at me while her mouth is open wide in song, and with a quick nod toward Marcus, hand gripping the armrest of his chair. Her nods signals, *Look at him!* He is showing all his teeth again, and his lips are stretched wide across them in a still mime of speech, but his tongue moves rapidly. I can see it move up and down, and to the side in time to the group's annunciation of words declaring 'Smile, boys, that's the style. What's the use of worrying? It never was worthwhile, so pack up your troubles in your old kit bag,

and smile, smile, smile!’

His wife looks at me; her eyes are bright and she tips her head toward her husband and bounces her shoulders in excitement. Her fingers are clasped in her husband’s strong, long fingers, and she leans her head against his shoulder to read the words off the songbooks. He looks down at her, and she sings, ‘Your old favourite!’ She will tell me the same thing at the end of session today, and I will reach for Marcus’ hand, leaning close to his face and say, ‘You were the best bass in the group!’

\* \* \*

This final chapter is a culmination of, and stands in opposition to, the chapters that have preceded it. The extended scene of a Singing for the Brain (SftB) session which I have presented above differs from the support group settings from which most of my ethnographic material has been drawn up till now. The most obvious difference is that at SftB sessions, people with dementia, carers and volunteers attend and participate together. Further, this chapter does not present an exploration of a temporality that fits inside a chronological organisation of past, present, and future. Rather, it seeks to explore a field outside this normative framing – liminality.

Drawing on my experiences attending and participating in (to debateable melodic success) SftB settings, I argue that the set-up of this group is a unique and carefully curated space that seeks to draw out and recognise connection and communality between all those who attend. As noted by Oliver Sacks in his book *Musicophilia*, "[t]ogether" is a crucial term, for a sense of community takes hold, and these patients who seemed incorrigibly isolated by their disease and dementia are able, at least for a while, to recognise and bond with others' (Sacks 2007: 344-345). I suggest that togetherness, or relational connection, is accomplished through a liminal space created by singing in which the importance of people with dementia showing a grasp of normative chronological categorisations of time in their communication styles and behaviours is de-emphasised. Indeed, behaviour exhibited during these sessions, often judged as nonsensical, embarrassing or inappropriate in the everyday spaces people occupied outwith them, become meaningful to carers and, importantly, often encouraged. The design of these sessions allows for novel and looser conceptions of what counts as doing 'the right thing at the right time'. I argue that this is because something greater was at stake than a desire for a person with dementia to 'behave' or 'act normal'. Significantly, attendees noted and celebrated behaviour seen to signify recollection of kin relations, memories, or a desire to connect to others. This suggests that my interlocutors actively seek relatedness in

and through these sessions as one of their main goals. Further, I suggest that signs of connection also served as the linchpin of carers' and volunteers' determination of whether a person with dementia is 'still there'.

Analytically, I position SftB sessions as liminal spaces, and approach an examination of SftB sessions as 'betwixt and between' (Turner 1967:93), in the sense that many of my informants saw these sessions as spaces away from, or outside the realms of, their everyday lives. The sessions offered both a temporal and a spatial seclusion, in that they were held in spaces not open to the public and created an experience of time not 'normal' in other contexts inhabited by 'everyone else', those 'who don't understand [dementia].' SftB sessions were 'a boundary, border, a transitional landscape' (Andrews and Roberts 2012:1) that attendees crossed into to evade normative rules of behaviour and cognition. My framing is informed by Victor Turner's work on liminality in rite and ritual (1967; Turner, Abrahams and Harris 1969) and his concept of 'liminoid' for 'modern' contexts (1982), which builds on Arnold van Gennep's triadic model of the rites of passage (1909).

Turner positioned liminality as a stage in transformational cultural processes, such as transitions from youth to adulthood, which destroy and ultimately re-construct

a new, or matured social status or identity of an individual (1982). My aim is not to cast SftB sessions as a rite or ritual belonging to a culture of dementia, but to use liminality as an analytic tool to examine how the established routine of SftB sessions unfolded in ways *akin* to the rites, and were able to create liminal spaces. Like many of the rites which Turner examined, SftB sessions are temporary, carefully crafted periods that begin and end consciously, and in this way also contrast with what other scholars have termed 'liminal hotspots' (Szokolczai 2000, 2017; Stenner, Greco and Motzkau 2017), or a state of temporary ambiguity that has become permanent. In further divergence from Turner's work on rites and ritual, I do not position these sessions, and the motivations of those who organise them, as aimed at permanently transforming people with dementia into 'new' subjects. Indeed, many of my interlocutors did not expect any permanent transformation of a person with dementia after a session, though some did note that 'he's more spry the rest of the day' and 'quicker with his thinking'. I instead suggest that the 'unfolding' and temporary nature of SftB afternoons gives rise to a particular type of *communal* experience marked by affection, connection, and behavioural spontaneity and freedom, which exists as a 'bubble' in the lives of the people with whom I worked. As such, an attention to transformation into something 'new' in Turner's approach to liminality would obscure what is happening in these sessions. I point instead to the surfacing of particular kinds of

relationality between those attending. Relationships which my informants had with one another, before dementia altered their lives, emerged through the transformation of all attendees into 'who someone is at their core', as described by one carer. Additionally, new kinds of 'togetherness' were made possible as people 'met him where he's at' during sessions, a refrain I heard from family members 'coming to grips' with changes wrought by dementia. Instead of 'new' persons, I suggest that it was these experiences of return to the familiar, as well as new moments of encountering one another that 'felt like before', that were sought in the liminal state of SftB sessions.

Considering these characteristics, I focus on the relational potential of liminality as 'fructile chaos, a storehouse of possibilities, not a random assemblage but a striving after new forms and structures...' (Turner 1967: 42). In so doing, my interest in the interplay between structure and antistructure parallels Turner's (1969), and I also trace the ways in which power dynamics are adjusted, or equalised in these sessions to build a particular sort of SftB *communitas* (Turner 1982). In particular, I draw out the organised efforts made to downplay cognitive differences and establish a social equality amongst attendees, against the backdrop of Fiona as 'master of ceremonies' (Turner et al. 1969: 21; Szokolczai 2014: 148) who guides and oversees the occasion. My examination of the



particular *communitas* of liminal SftB sessions is also informed by work on sociality and communication in dementia contexts. I draw on Tolhurst et al's work on narrative collisions and couples' use of language, such as the word 'we', in describing their experiences, 'which indicates the aim to co-construct a congruent joint narrative' and create a sense of unity (Tolhurst et al. 2017: 223; see also Hydén and Nilsson 2015). Tolhurst et al's research focused on narrative constructions in dyadic interview settings, whereas SftB sessions diverge in that verbal, conversational dialogue was not its foregrounded feature, nor, do I suggest, was narrative. However, his emphasis on co-construction in conversational strategies is helpful in unpacking how carers and people with dementia seek co-construction in other forms during SftB afternoons. I link this to the kinds of behaviour allowed for and encouraged in these sessions, and suggest they expanded the communicative range of people with dementia and potential for social connection between them and their carers. As such, this chapter sits within work that has shown the positive significance of dementia care practices that recognise ongoing communicative capacities and embodied histories without insisting on continuity of other forms, particularly memory (Basting 2009; Chatterjee 2006; Clare and Shakespeare 2004; McLean 2006, 2007; Taylor 2008).

This chapter also explores how different modes of interaction and communication in this liminal space gain traction in determining someone's 'there-ness'. As discussed earlier in this thesis, the ability to communicate desires, opinions and needs and recognitions of care signals a sense of relational connection, which links to others' conceptions of personhood or 'there-ness' (Taylor 2008) and protect against conceptions of social death (Kaufman 1986). Considering the link between being seen as able to communicate and being a social subject, greater communicative range generates novel opportunities for recognitions of personhood. Further, I suggest that not needing to iterate narrative or remember biographies and histories of relations in normative ways, as well as an atmosphere of social equality, allows for more intimate, forms of communication to emerge in these sessions. I propose that this liminal space is more hospitable to tenderness and love defined on their own terms, and not only as practices of care. Brijnath's work on elder and dementia care in India (2014) and her concluding chapter in which she explores moments of romantic love between spousal carers and their partners with dementia, served as an early inspiration for this chapter. This chapter is, in part, an answer to her call for greater anthropological attention to the romance of love, on its own terms, outside the less 'taboo' attention to 'affect, relationality, reciprocity, cohesion, and exchange, about the substantive processes of love such as family planning, blood and kinship, childcare, eldercare,

domesticity; and the commodification of love...' (2014: 184). In allowing for moments of love to surface, I show that the integrity of *both* carers and people with dementia's personhood and agency are asserted. In line with earlier chapters, I examine the entanglement between personhood and modes of communication as an interplay between people's need to be subjects separate from one another, but also, at the same time, in meaningful contact.

Lastly, I touch on the hazards of an analytic approach centred on liminality. While my interlocutors described SftB sessions as 'affirming', 'relaxing' and 'fun', I wish to avoid the trap of casting them as uncomplicatedly positive in light of their liminality, as others have warned against (Horvath, Thomassen and Wydra 2015). Further, Tolhurst et al. argue that 'there is a trend within academic discourse...[in which] the academic promotion of personhood is aligned with resistance to excessively discouraging representations of dementia...reinforced by a policy discourse associated with 'living well' with dementia (Department of Health 2009)' (Tolhurst et al. 2017: 223). This is important to consider, particularly since I have chosen to write the final chapter of this thesis about SftB spaces in emotive language, drawing out themes of affection, love, fun and respite. Indeed, in this respect, this chapter is a departure from the chapters that have preceded it. A

vignette and analysis of 'singing afternoons' runs the risk of being a rose-coloured attempt to end this thesis on an uplifting high note.

To avoid falling into the trends Horvast and Tolhurst et al. have identified, and to avoid simplifying my informants' struggles, it must be made clear that they also felt uncertainty and grief during these sessions, linked to the affective and emotional nature of these nostalgic gatherings. It must be remembered that SftB spaces were unique and carefully constructed, and the experiences they gave rise to were considered special, and rare. These experiences were not often the norms of people's everyday lives. Bearing this in mind, it is important to note that despite this pain, these groups were the most well-attended, with the highest attendance of the same members, and enthusiastically praised of any Alzheimer's Society function I attended over the course of my fieldwork. In terms of consistent attendance, it most closely rivals the groups for person with dementia I visited, and two of the Caring Cafés I attended with well-established carer support groups and frequent musical guests that performed after lunch. I have therefore chosen SftB settings as the focus of my final chapter because it underlines my interlocutors' pursuit of positive experiences and gives us an insight into how these positive experiences were brought about. Thus, this chapter shows that positive experiences of ease, laughter, joy, affection, gain and connectedness did

happen, and do exist. This is all the more remarkable considering the backdrop of hard work, strain and uncertainty involved in being able to reminisce, reach and remember one another.

To begin, I explore how the volunteers and other attendees of SftB sessions sought to create an atmosphere of social equality and communality. I show that this was done by down-playing distinctions between those living with a diagnosis of dementia and the 'cognitively well'. Focusing on subtle practices that acknowledged people's personal preferences in tea and musical instruments, I underline the significance of individuality in the recognition and establishment of attendees' standing as valid social subjects. Building on this, I then demonstrate the part individuality plays in the making of a pervasive relationality of commonality and communality amongst SftB members. In the next section, my focus turns to activity at the heart of SftB meetings: singing. I position singing as a collective activity through which liminality was forged in these sessions. Through a focus on what attendees paid attention to during singing, I point out that an interest in whether people with dementia could remember and narrativise the past accurately was replaced with an interest in their ability to partake in the collective activity of reminiscence created through the singing of nostalgic and war-time songs. I link this to discussions in earlier chapters' of personhood as intrinsically

individual *and* relational, and to Taylor's work on the importance of recognition to personhood in dementia contexts (2008). The final section centres on the topic of love and affection and focusses on how these qualities make themselves present during these afternoons, and how this might mirror the most intimate spaces of people's lives away from group settings. I position love and affection as tenors of connection and communication my interlocutors sought, and show the ways in which liminal spaces made the experiences and recognition of these feelings possible. My hope is that in this illustration of my time spent in these groups, the people from my field will read this and see themselves beyond ethnographic objects, which our work necessarily creates of those who have so generously shared the intimacy of their lives with us.

### **The Construction of SftB: the play between commonality and individuality**

I chose a Singing for the Brain group as the focal point of this chapter because it is unique to where I spent most volunteering in the field: it is a determinedly and unapologetically social and a much-anticipated get-together for all who attended. They were *fun*, and this showed in a myriad of subtle and visceral ways. There were no explicit references made to these sessions being a therapeutic space or 'support' for carers (though some carers did allude to their 'respite' qualities,

which I discuss later in this chapter). While other services, particularly Caring Cafés and support groups, always had a wide variety of pamphlets on display, such as 'Preventing Falls', 'Planning for the Future: Medical Directives and Power of Attorney,' or for local care homes, SftB only had a few black and white printed sheets with discussion topic prompts, such as 'Before everyone had televisions, people went to watch films as a special occasion. Did you have a favourite film when you were young?' strewn about on tables, akin to some Caring Café afternoons. In this, the prioritisation of social interactions during these afternoons was signalled and worked to establish an equality of social participation and expectation of attendees' ability to interact. I suggest these features are an effort to form a particular kind of SftB 'liminal group' composed of 'a community or comity of comrades and not a structure of hierarchically arrayed positions' (Turner 1967: 100).

At the same time, pervasive norms to acknowledge attendees' individuality by categories other than dementia diagnosis, which many people in my fieldsite found frustrating, allowed SftB sessions 'to ignore, reverse, cut across, or occur outside of structural relationships...representing the desire for a total, unmediated relationship which nevertheless does not submerge one in the other but safeguards their uniqueness in the very act of realising their commonness' (Turner

1974: 274). SftB *communitas* stands in contrast to, or is 'the anti-structure' (Turner 1974) of my informants' experiences outside this group in which people with dementia are often treated as diminished social subjects and 'talked over, like he's not even there'. In Turner's rendering, *communitas* and liminality are tandem components of anti-structure.

### *Communality through Social Equity*

As can be seen in the opening vignette, staff and volunteers made efforts to warmly welcome all attendees to the sessions. This established a common social ground among attendees: there were no clear social interaction delineations between carers, people with dementia, staff, and volunteers. In general, people milled around the room, occupying the same physical space and no separate carers' support group was held in an adjacent room during the SftB session which is often the case in Caring Café services. Instead, both carers and people with dementia took part in the group. Carers whose relative with dementia had passed away continued in their attendance for a period of time afterwards, with some becoming official volunteers. People with dementia often arrived on their own, or accompanied by more than one family member. In line with previous chapters' discussions about the gendered nature of care, it was most often the daughter of



a person with dementia who accompanied their parents. They often helped the volunteers by fetching tea and coffee, setting out chairs etc. and families with multiple daughters who chose to attend 'took it in turns to come along'. Before the singing began, people sat around the room and enjoyed their tea or coffee and biscuits, and talked to each other. Smaller groups formed that expanded and contracted as new people arrived. As most attendees attended with a high level of consistency, staff were often asked about those that were missing. People from different families, regardless of whether they had a dementia diagnosis, talked to each other, sharing updates from the week, and trading gossip about the goings-on of their lives.

Physical help was given to people with dementia and carers alike who had trouble sitting and standing on their own or walking across the room. Many volunteers kept a watchful eye on all attendees to anticipate a need for assistance, which seemed to centre more on attendees' age and mobility, rather than dementia diagnosis status. Interestingly, assistive touching and help was discouraged by AS head staff (who intermittently visited to conduct 'quality of service checks'), on the grounds that help offered might instead cause injury, with 'falls' mentioned frequently. These official recommendations and guidance usually garnered a subtle eye roll from volunteers and some of staff, and prompted commentary that

the head office was 'just worrying about liability'. In practice, they were quickly forgotten after a 'quality check' visit, and volunteers quickly resumed offering physical assistance and sometimes dancing with attendees during the singing stage. As such, ordinary bodily boundaries maintained in support group settings and between 'strangers' in outside public spaces were blurred in SftB groups. In effect, this group felt friendlier, more social and equitable, and generated a sense of familiar intimacy that went beyond what I witnessed in other groups and services. I suggest that SftB's looser norms concerning physical touch and equal sociality allowed for the love, tenderness and affection that emerged during singing, as will be discussed in a later section.

### *Individuality through Preference*

Volunteers who took on the role of welcoming people to the room where SftB was held, made efforts to recognise each person individually. People were welcomed by name, and by tea and coffee orders, mentioned in previous chapters, were a focal point of how attendees were welcomed, and preferences marked. Almost everyone had a drink preference, and beyond that, a specific recipe to their taste. In the vignette which opens this chapter, my movement through the room and interactions with attendees centred on my gathering,

making and delivering these distinct drink orders. The description draws out my own enjoyment of this task, but also the amusement and conviviality garnered through interactions that recognised and remembered preferences. Recall my verbal volley with Bill, whose favourite is a 'weak and sweet' coffee. In fact, my private field-notes are littered with anonymised pseudonyms based on these preferences. Quotes by and observations about people are often marked with shorthands such as TSNM (tea, sugar, no milk), CSB (coffee, sugar, black), TNSLM (tea, no sugar, little milk), or CSSSM (coffee, sugar sugar sugar!, milk). Attendees, and particularly people with dementia, became marked as unique subjects with individual personalities and perspectives through an attention to tea and coffee orders.

Musical instruments also marked preferences and became a means by which to acknowledge individuality. Compared to tea and coffee orders, far fewer people had as strong partialities over instruments but there were known preferences. Tom always wanted the drum, Millie and Fiona always chose bells, and David preferred the wooden toad, and I learned from the more senior volunteer to subtly 'save' these for them. While people with dementia, carers and volunteers alike had favourites, this was also an arena in which there was a subtle difference in attention paid to participants who had dementia and those who did not. In

general, volunteers avoided giving people with dementia instruments that had more than one component (such as a triangle, wooden toad or clapping sticks) in case the coordination needed caused confusion or interrupted their singing. As such, instruments as markers of individuality came to be based on preferences, but also informed by perceived ability. It is important to note, however, that the appropriateness of an instrument was also adjusted for anyone who was holding hands or might be holding the songbook between a pair, which applied to both carers and people with dementia. This effectively blurred any obvious lines that might have been created between 'complicated' and 'simple' instruments based on perceived dementia-affected ability, thus sustaining an atmosphere of commonality and the sense that everyone was a valid social subject. An attention to instrument selection also points to the ways people occupied this space relationally: holding hands was an 'equal opportunity' activity. In fact, I preferred the one-handed Easter egg for this reason.

### *Commonality and Individuality Intertwined*

Regard for commonality and individuality subtly pervaded the ways in which people interacted with one another and inhabited the duration and space of SftB sessions, so that they are able to operate contrary to many of the norms of society

that my interlocutors face due to their association with dementia. When volunteers customised their actions toward carers and people with dementia according to their preferences 'because he's his own person', this mode of behaviour also engendered commonality because *everyone's* preferences were attended to. Likewise, the cohesion and sense of shared experience of this group that lent it an ethos of social equity also depended on people showing up and lending their unique personality to the social interplay of the group. Hence, commonality and individuality are mutually constitutive elements of SftB as a liminal group and this is clear during the time of singing. For example, carers, people with dementia, staff and volunteers alike would shout out song requests, signalling an equal opportunity free-for-all of 'getting to sing your favourite'. This was how the group decided together which songs to finish the session with, and people encouraged one another to offer their favourite song and then rallied behind people's preferences. This was done with a remarkable politeness and sense of fun. It was not a competition to have one's own preference chosen, and instead it seemed that people around the group shouted out preferences or seconded others' out of enjoyment of making a ruckus of shouts and calls. Sometimes, shyer members of the group or a person with language difficulties might have their requests championed by another person. The family members and friends of a few people in the group who no longer had the ability to speak

in verbally coherent ways would remark 'oh, that's always been a favourite of his'. After comments like this, they often then watched for signs of an embodied recognition of the song, such as mouthing the words, or moving their hands. A few months into my volunteering at this group, after I had established rapport with a number of attendees, this inclusionary custom was even extended to me on a few occasions. The first time, a carer nudged me in the ribs and shouted, 'Lilian wants to sing the Skye Boat Song *again!*' and winked at me to acknowledge my embarrassment at asking the group to sing my favourite song twice in one session.

These incidents echo discussions in previous chapters about the importance of personal distinctiveness in relationships between people. I point to many carers' resolute stance that others 'couldn't take care of him as well as I can – because they don't know him like I do', as well as many of the biographically-centred conversations in support groups for people with dementia. In all of these, the significance of personal, individual opinion, preference, viewpoint and experience is clear. Amongst carers, 'knowing the way she likes things' was linked to 'good' care, highlighting that good care was that which was personally tailored and not only met health-related needs, but acknowledged a person's uniqueness and idiosyncrasies. In support groups for people with dementia, it was learning about

and knowing the minute, distinctive details about one another that bonded members as a group. Notably, these details were about people's histories and families, not particularities about their dementia, akin to carers' 'interpretive caring' (Perry 2002) allowing them to decipher the meaning of 'odd' behaviours through a consideration of their person's history. The principal point here is that my interlocutors sought ways to socialise that were not negated or made embarrassing by dementia, but instead celebrated the individual as intact and functioning.

Thus more unusual behaviours are not shushed or suppressed during SftB sessions. Recall Howard's shouts of 'TRA LA' and marching around in circles like a sergeant, Marcus' loud squawking noises, and exuberant displays of affection (such as not letting go of someone's hand and kisses). When such behaviour arose during the singing, new members sometimes looked confused or alarmed, or worked to stifle an embarrassed laugh, but then looked to others in the group to gauge their reactions to the odd behaviour. In almost all cases, veteran attendees seemed unperturbed by such behaviour, and even encouraged it. These instances in which odd behaviour was signalled as 'allowed' were ones of learning for new members. The range of social behaviour normative to the group was marked as greater than and different from what structured 'ordinary' society beyond the

temporal and spatial confines of SftB sessions. In this way, the liminality of SftB sessions was both cued, and protected against encroaching judgments of 'people who don't understand [about dementia]'. Interestingly, certain 'odd' behaviours became expected habits of different people and seen as a part of their personality. Thus individuality was not so easily negated by what might be seen as bizarre behaviour in other contexts and hidden behind the homogenising label of dementia. Incorporating this behaviour in the group, while also linking it to personality, further cemented SftB as a social group populated by independent actors, striking the balance of liminal *communitas*.

A pervading focus of this thesis has been chronological narrative and its significance as a framework by which people seek to organise their experiences. I turn again to this theme to examine the activity of singing, to show that communication between SftB members came to centre on features other than chronology. In this, the lack of strict social delineations based on status and an ethos of non-judgement of odd dementia behaviour become important. They allow for the suspension of strict distinctions made between those able to 'accurately' relate to time and those impeded by cognitive challenges in 'making sense' of time. I suggest that this absence of expectations that people's communication should follow normative understandings of time and chronology



(which was apparent in other settings of my fieldwork) created a quality of temporal liminality during SftB sessions. This quality is made most clear in SftB singing as collective activity centred on *reminiscence*, which I position as a temporally 'blurry' activity and experience wherein seemingly nonsensical noises, movements and touch could be deemed meaningful and communicative. Significantly, reminiscence as a topic of study is also blurry, informed by a range of divergent interdisciplinary research.

#### *Reminiscence – a 'blurry' topic of study*

Considering the range of interdisciplinary attention to the topic of reminiscence, and the various meanings and purpose to which it has been put, I use the term carefully. In common parlance, it means reflection on the past, obscuring its significance as an experience of the here and now. Further, I suggest this positions the 'past' as a memory conjured up and held in the mind through cognitive skill. This reinforces chronological renderings of time, and works against my description of SftB settings as a temporally liminal space that de-emphasises linear experiences of time. Instead, I use the term to refer to the interactive, embodied activity in which attendees remembered experiences from over the course of their life. Their embodiment or becoming 'caught up' in the experiences and emotions associated with the war-time songs, for example, is not a function

of understanding time as linear, but instead one that brings the past into the present and 'takes someone back'. This echoes Webster's psychological research on reminiscence which highlights the overlaps between the past and present in reminiscence among people across the life course (2003).

Akin to cross-disciplinary researchers interested in reminiscence in dementia contexts (Elliott and Gardner 2016; Gonzalez et al. 2015; Lai et al. 2004; Serrani 2012; Tadaka and Kanagawa 2007; Wang 2007; Woods et al. 2018), I also position reminiscence as an *activity*, as well as an experience. Further, I highlight that reminiscence is a participatory activity to be *witnessed* by others, but this interpretation diverges significantly from these researchers in that I do not approach it as a therapeutic intervention as such. My aim is not to assess its efficacy, or focus on standardised outcomes of mood, depressive symptoms and agitation. Further, and perhaps most significantly, my positioning of reminiscence as an activity that fosters temporal liminality stands in stark contrast to research on reminiscence therapy (RT) that advocates its use in making sense of a person's relationship with their past and fostering a 'proper' meaning of the past in the person cognitively affected by dementia (Lin et al. 2003).

Research specifically on singing and reminiscence is limited, with most focusing on either singing or reminiscence activities. However, a six-week pilot programme called 'My Musical Memories Reminiscence Programme' (MMMRP) was organised by the England Alzheimer's Society (Evans et al. 2017), modelled on the Alzheimer's Society *Singing for the Brain* sessions. The model of the pilot study differed from SftB groups I attended in that only people with dementia and trained volunteers attended, family carers were separated into a different room, and visual memory aids and personal photographs were used. However its findings that reminiscence and singing foster interaction amongst, and participation by, people with dementia, and foreground attendees' enthusiasm for the positive relationality created by these sessions, echo my own. The MMMRP study was centred on creating personalised playlists of 'music that was familiar and meaningful to them' (Evans et al. 2017: 3), in line with Gerdner's theory of Individualised Music Intervention for Agitation (IMIA), which suggests that music must be personalised to a person's preference and life history in order to elicit memories (2000). Others have also pointed out the strong association which music can often have with phases or important events in one's life, therefore helping to trigger recollection of past memories (Cuddy, Sikka and Vanstone 2015; Dempsey et al. 2014; DeNora 2013; Sacks 2007).

This personalised approach also aligns with the set-up of SftB sessions. The war time era songs were nostalgic and meant to be familiar to attendees as they fit the demographic background of most of the attendees, who were, mostly, white British in their 70s and 80s. Moreover, the same songbook and often the same 20 songs were chosen, highlighting that beyond familiarity of life history, my informants also valued songs' familiar association with the space of SftB. Indeed, a few months before I finished fieldwork, a new SftB music leader joined to replace Fiona, and brought a new selection of songs from his experiences living and playing music abroad. Some of them were not in English and all were unfamiliar to group members, and many people – carers, people with dementia, and volunteers- quietly complained to one another for several weeks, with some pointedly choosing songs from the old songbook to finish off the sessions. The set of songs lead by the new teacher gradually moved back to the original selection, and a few people commented to me that they were pleased that things were back to the way they were:

Howard [husband with dementia] and I weren't enjoying it as much, almost felt like work...having to come and learn something new, instead of just a bit of fun and memories. I could tell he wasn't interested. [Lilian: How so?]-oh, he couldn't sing along really, the beat was off, and it was work for

me to try and get him to pay attention, and you saw him - he'd get restless to leave.

This links to findings of music as a conduit of non-verbal communication, particularly in dementia contexts, that can help to improve mood and wellbeing (Blackburn & Bradshaw 2014; Evans et al. 2017; Gerdner & McBride 2015; van der Vleuten, Visser and Meeuwesen 2012; Särkämö et al. 2014) material shows that music was also a conduit of non-verbal communication, which played a significant role in carers' enjoyment of these sessions as well.

### *Reminiscence Instead of Temporal Testing*

In previous chapters, I have discussed the ways in which carers and people with dementia worry about and assess whether they are 'making sense of' time, and how this links to constructions of personhood. With SftB sessions, their temporally blurry qualities allow hegemonic renderings of time to be suspended. This is because during SftB sessions, singing is not an activity reliant on narrative structures. Attendees' temporal experience can slip between past and present through songs that draw on embodied memories of the second World War. For many people, these were the songs of a time when their lives were in a state of flux and many related (both through words and actions) the emotions they felt,

their memories or associations to the song while singing. Recall Howard's marching around the room like a young soldier while singing 'TRALALA', which I position as a participatory activity of embodied recall. People with dementia were not asked questions to determine whether they are 'lost', whether he 'thinks he's really in the RAF', or whether they recognise others. Thus, a person with dementia's accurate understanding of the chronological movement of time, and where along this timeline the present currently resides, is not actively 'checked for.' Carers' and volunteers' actions during a SftB session suggest that they evaluate whether a person with dementia 'is there or not' by a different metric.

In SftB sessions and in other, intimate realms of people's lives, what came to matter was whether a person was anchored to the social space through singing which is 'going on right now'. Recall and memory were still significant, but people seemed most interested in how these capacities surfaced in participatory ways that marked one's ability to be a social actor. Methods to gauge reminiscence can be seen in how carers and volunteers watch their person with dementia in subtle ways. They watch their mouths to see if they are singing along from memory, at their eyes to see if they're following the lyrics on the pages of the songbook, and at their hands to watch them percuss their instrument in time to the music. On the surface it may seem as though this attention to embodied reminiscence is

actually another measure by which carers and volunteers are checking to see if a person with dementia 'remembers' the past through a reliance on memory.

However, participation in the activity of this group is different from the type of memory work my interlocutors are expected to do, and could routinely fail at, in realms of their life outside these afternoons and in Reminiscence Therapy interventions. Singing along is not an exercise in recalling and iterating information purely about the past or one's biographical identity. It does not illustrate to others that they understand the difference between the past and present. Carers and volunteers instead watch the bodies of people with dementia for signs that they recognise that this is a space of mutual enactment of past memories, and that they are participating as genuine social actors. This parallels Oliver Sacks' examination of singing and dementia in which he writes, 'Woody seems to be tiring of questions to which he could not supply an answer (such as, "Can you read this?" or "Where were you born?"), so I asked him to sing...When Woody sang, he showed all the expressions, emotions, and postures appropriate to the song to singing in a group – turning to the others, awaiting their cues, and so on' (Sacks 2007: 340).

Further, everyone in attendance is able to participate in this type of reminiscence

because the group is constructed as a socially cohesive and equitable space. Certain ways of being in time are not privileged as they are in other contexts. People with dementia do not come alive in the past, they 'come alive' by mutual enactment of memories.

*Witnessing Reminiscence: recognising personhood, unbinding dichotomies of care*

SftB members also sought confirmation and celebration of active reminiscence and social interaction from each other. They looked across the room to one another and indicated this with head tilts and smiles during the session, or commented, 'Look, he remembers all the words!', 'see that, she doesn't even need to look at the book', or 'this one was always one of our favourites', and carers often linked these signs to comments such as, 'He was really there during today's session!' This is seen clearly in Susan's elation when Marcus, her husband with dementia who is unable to speak coherent words, was mouthing the words along with the group, as described in the ethnographic material earlier. Yet while carers did look to others to mutually witness reminiscence, most SftB service users sought participation in reminiscence with their carer or person with dementia most of all. They would look into each other's faces, bounce their held hands in



time to the music, dance with one another, have fun teasing one another by shouting out one another's favourite songs, and goofily act out parts of the songs. This was done with obvious joy, fun and pleasure. People laughed and, at times, the delight people felt almost turned heady and seemed to redouble people's efforts to connect. It was during such afternoons in which an attendee with dementia spent significant time interacting with their carer or others in the group that mutual confirmations of 'there-ness' were strongest.

Moments in which carers witnessed a person with dementia's participation with delight and relief, corroborated these moments with others, and also became absorbed in their interaction with their relative, relate to earlier discussions in this thesis. The significance of recognition of shared histories and reciprocation of care between people in making determinations of personhood (Taylor 2008) is pertinent here. Personhood is made in the back-and-forth relational space between individuals and not in an assumed, 'given' quality granted to people outright. This recognition of the importance of interaction as an indicator of personhood in and of itself is powerful because it shows that personhood is not necessarily bounded by time. Here, it is instead bounded by the ways in which through *communitas* a group recognises certain behaviours and modes of interaction and communication as meaningful.

In examining how interaction comes to take on new forms and significance in spaces of liminality, and specifically in temporal liminality, I suggest that attendees shed temporarily some of their identity as objects of, or providers of, care. Associations of dependency and care were loosened when attendees with dementia were given status as intentional social agents in recognition of their personal preferences and contributions to social cohesion. In turn, when people with dementia became seen less as objects of care, carers and even volunteers were also able to partly shed their identity as carers. Normative expectations that carers wholly centre their actions and concerns on their person with dementia's behaviour and needs were shifted. The unique personalities of both the person with dementia and the carer were established and tied less to dementia in this space. The connection between them could then hold possibilities other than the carer/cared-for dichotomy. In the next section, I discuss how this was linked to moments and acts of tenderness and love.

### **Love and Tenderness in Liminality**

In this section I explore how the emotive ways that people connected with one another during SftB sessions resonated with tenderness and affection beyond

carer/cared-for dichotomies. Tenderness and love played out in the interactive space between attendees reinforced the group's *communitas* and people's status as equitable social agents possessing personhood. Practices of care in dementia management are not the only expressions of love available to these families, but that love exists on its own terms beyond connotations informed by illness. I explore love as a concept that exists outside of time, and compare it with practices of care which are more closely anchored to linear, chronological renderings of time. I position this exploration of love, tenderness and affection as an artefact of the SftB liminality, which resembles some of the most significant intimate moments between carers and people with dementia described in support settings. I thus argue that SftB sessions do not necessarily invent a new space in people's lives, but instead serve to bring experiences sometimes had in the privacy of one's home into the secure social space of SftB sessions.

### *Communication of, and through, tenderness and affection*

As the opening description showed, I was often greeted with affection and was frequently touched at SftB sessions. I, in turn, greeted others with affection and touched people more than I would at other Alzheimer's Society services. For example, in my encounter with Delia, touch and tenderness were undeniably the

basic elements of communication and greeting. Our words were less significant, and in fact Delia's verbal range is limited. Her most frequent expressions are 'I love you!' and 'God bless you!' Other similar instances of communication included attendees signalling of hello to others, or excitement for singing to start with a lift and shake of their walking stick. Further, helping one another to their chairs was often a fairly equal opportunity form of chivalry, in that a number of men with dementia led their wives to chairs, holding them stationary as they sat. In the absence of a robust linguistic vocabulary to draw on, the communicative power of touch, and even examples of touch which in other contexts may be seen as awkward, or 'over the top', is highlighted.

Indeed, there were instances in which a person may have been jokingly referred to by others as 'a bit over the top'. For example, Herman would often draw multiple women from around the circle into a dance, or some attendees with dementia (always men) on very rare occasions would seemingly nonchalantly rest a hand on my knee or lower thigh, or so low on my back I could not help but raise an eyebrow. However, when I discussed these instances with other volunteers, AS staff or carers, their reactions never *explicitly* labelled these behaviours as signs or symptoms of dementia. Instead, Herman's enthusiasm for his dance partners or some men's penchant for certain parts of my body were marked as Herman's

boisterous personality, or 'Men are like that, aren't they? – some never change' and 'I'll sit next to Todd next week, love – he won't want to touch an old one, like me! [laughs].' Thus, despite some examples in which communication was seen to push against some social boundaries of typical or sanctioned levels of friendliness, these types of touch were instead positioned as expressive of a person's personality or gender. It bears noting here that the interpretation or significance of instances like these by SftB attendees are probably informed by norms of behaviour to the particular generation of my interlocutors, as well as pervading notions that women's touch is deemed more innocuous than men's. My own curiosity at the general lack of concern raised over men's behaviour is perhaps indicative of my position as a relatively young white woman in the era of the #MeToo movement<sup>2</sup>. Such instances were rare and constituted the more extreme examples, but nonetheless show that an ethos of suspending judgment of behaviours even at the 'outer limits' characterised this group. Thus, people's communication and expressive agency were broadened by this space's normalisation of unexpected behaviours and a sense of social equity, which gave credence to the inferred meaning of Delia's and others' touch.

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<sup>2</sup> The #MeToo movement is began in 2017 that aims to to demonstrate the widespread prevalence of sexual assault and harassment, especially in the workplace. It first gained momentum as a hashtag on the social media platform Twitter, following sexual abuse accusations against Harvey Weinstein, a well-known Hollywood producer. Since then, it has been used by a people in a wide variety of contexts, from educational settings to the military.

A more intimate example of tenderness and love through touch can be seen in the interactions between Marcus and his wife, Susan. Marcus' difficulty with speech was one of the most progressed in the group, but he and Susan nonetheless interacted. During the entire singing session, they held hands and sat close together despite the obstacle of his wheelchair. Her hand was grasped strongly in his, and he tilted his head to look down at her often, his eyes wide while he opened and closed his jaw. In return, Gloria frequently responded to her husband's participation in the singing and grabbing hold of her hand. She returned the pressure of his grasp in equal measure and rested her head on his shoulder, sometimes also stroking his chest in small clockwise circles. When I first noticed this, I found these subtle acts of tenderness and affection startling and striking. They illustrated and created an intimacy I rarely saw at other service events at which I volunteered. I became keenly aware that although Marcus has dementia, he is also a husband, and that Gloria cares for his needs, but she is also his wife. In this relaxed environment, in which Marcus did not have to prove his grasp on temporality or become hidden by his 'symptoms', touch and tenderness could be more closely read as originating from their identities as husband and wife.

People around the group would subtly smile and nod to one another in recognition of Marcus and his wife when they were sweet to one other, and comment on it later, in ways similar to members' acknowledgement of participation in singing. Likewise, when people with dementia partake in acts of tenderness and love, their 'there-ness' or personhood was highlighted in attendees' positive comments that drew out their roles as both recipient and sources of interaction, such as, 'They're still such a loving couple, aren't they?' and 'You can tell she knows she's being looked after'. Further, in my greeting with Delia, for example, I was mainly the recipient of her tenderness, which is different from most depictions which paint people with dementia as chronically in need of care and attention. As such, my analysis supports other work showing that communally participating in reminiscing in contexts of dementia can improve communication and social engagement, and foster interaction between attendees (Dempsey et al. 2014), and those with long-standing relationships.

*Love on its own terms; Love beyond time.*

The liminality of SftB sessions allowed for expression and reciprocation of love to be sought in tender interactions and affectionate touching and expressed on its

own terms, for its own purposes, and not simply as a powerful motivator to continue to provide care. This contrasts with earlier discussions in this thesis, in which love was often referenced as a motivating force underlying 'why' someone is a carer, alongside a moral obligation to care based on kin bonds which kept carers 'doing what we do, really - because it really can get quite awful and hard'. Notably, these latter comments were made in the specific spaces of carer support groups, which were particularly focused on the subject of dementia and cast their participants as 'carers' and a person with dementia as their object of care. Unsurprisingly, this affected the ways in which care and love came to be bound together in the majority of spaces where I conducted research. The significance of a softening of delineations between carers and cared-for persons can also be seen in the ways in which all attendees described the SftB service as respite and relief. SftB gave people respite from societal expectations that a carer would constantly watch over and manage a person with dementia's behaviour, and that a person with dementia would acquiesce to being constantly monitored.

People with dementia made comments to me such as, 'Oh, I like coming, because nobody's asking me all these things I should remember!' with a chuckle, or 'It's nice to have someplace to go, you know, where they're not nervous around you – some of my friends have stuck around, but a lot think that just because I have



memory problems now, they can't come around.' A good number of people with dementia came to the group alone and in speaking about why they liked coming every week, said that they like 'meeting with friends – catching up, nice to have a hug [chuckle]'. Ample positive feedback linked to these themes from participants with dementia was also found in the MMRP pilot study described earlier and highlighted that attendees with dementia ignored possible obstacles, such as pain, in order to attend. People came to SftB because it offered a respite from social isolation. They came seeking conviviality for its own sake. Carers also enjoyed catching up with friends and 'seeing something besides the walls of our flat all day!' SftB sessions offer a perspective of affection and love being defined and enacted as a consequence of people's interactions with one another rather than primarily as variant modes of care, or in contexts of care.

### *Love beyond time*

Brijnanth's (2014) call for greater inclusion of elderly people as subjects in studies of love and romance (never mind the lack of representation of people with dementia) is pertinent here. On a number of occasions, in conversations with carers after support group meetings or Caring Café events, I was taken aside and told to 'make sure you write about love in your research' because '...this is all

about love!' Indeed, in the course of long and intimate interviews with carers and people with dementia, the subject of love often came up and, while linked to motivations to care, people also spoke about how they worked to continue to express love in ways that matched their historical relationship with their loved one.

For example, in one interview, I sat with Paul, in his sitting room while his wife, Rita, and their professional helper meandered between the area we were in and its surrounding rooms. Rita did not string more than four or five words together at any one time, but from her short phrases, her husband was able to punctuate our interview with insights such as, 'She's wanting to go our old house...she's a bit confused', 'She's getting hungry I think...Rita, maybe a few biscuits?' He also told me that he does

things to make sure she doesn't just become some institutionalised person, you know, that just sits in a chair at the day centre all day, so I try to do things so she's still a person, my wife. [Sly grin.] I flirt with her, give her a little pat on the bum when she goes by, to make her giggle, you know, and...feel like a woman. And sometimes we dance. I'll put on music – my son's a musician – and we'll dance together...[He gets up and takes his wife's hand, and slowly twirls her to face him]

and she's my Rita – [turning to Rita] when it's just us and the music  
the rest doesn't matter so much.'

At this, Rita turned to look into her husband's face and strung together a few sounds that I did not understand; however, Paul smiled at her and lingered, before turning to smile at me.

Here I was offered a glimpse of a couple living with and managing dementia, inhabiting a space beyond time. When Paul took Rita's hand, she stopped wandering, ostensibly searching for rooms she recognised from her past, just as he stopped following her with his eyes as she moved from room to room. In the brief moments that they gently swayed to the music, Rita's hand found his and they looked in sync. They appeared to inhabit the same liminal space, a space that did not include the walls of their house that agitated Rita with their unfamiliarity, nor the professional helper who waited patiently in the doorway of the room, nor me on the couch asking incessant questions about dementia and care. These moments seemed closed and occupied by two individual people who were linked and deeply aware of one another. The space opened up again only at Paul's recognition of me with his smile. His glance to me again traces the ways in which personhood, or 'there-ness', is granted by another's acknowledgement of the

back-and-forth between social agents.

In another interview, a woman recounted a recent experience she had had when she had woken to her husband's night-time coughing. She had fetched a glass of water, and helped him to drink. In the dim light of a darkened room, 'He reached out and touched my face and said, 'hello' and 'you look tired, tired, tired' and some other nonsense, but softly...like a lullaby.' This carer cried as she expressed her relief that, 'Oh, he can see how tired I am, he knows I'm here – he cares...loves me.' She told me, 'sometimes he's still there'. This story illustrates what happens when carers construct a relationship with their person with dementia based on seeing care between them as still being present, if perhaps altered. In such stories the importance of referencing and remembering shared memories becomes less valuable than the ways in which people can be in the world corporeally and express themselves beyond coherent cognition. The woman saw her husband's touch, his recognition of her exhaustion, and his lullaby murmuring as an act of care, underscoring the entanglement between love and care, but also the significance of care based on an historical kin relationship, instead of care as a honed practice necessary because of dementia. She discerned that he recognised her and thus she granted him 'there-ness' because he was a person in his own right, proven by his care for her. These moments' similarity to SftB sessions, as

well as their tenor of the transcendental, reveal that by moving beyond the linearity of time, my informants 'find' one another.

## Conclusion

Returning to Turner's original usage of the term (1956), liminality emerges in conjunction with a *communitas* that works to establish a setting and a group as an 'antistructure' of the normative rules of the society in which group members live their everyday life. This chapter has traced the ways in which SftB sessions mirror this concept, highlighting their ethos of social equity over cognitive categories, and the recognition of individuality through attention to preference, personality and life history. I have also noted where Turner's framing of liminality does not fit: the aim of SftB sessions was not to make new persons at the end of this 'rite' but to make persons 'come alive again' as full social subjects within the duration of the sessions, and most importantly, to 'come alive' for and with family members in attendance through meaningful connection.

I have shown that one of the several distinctive qualities of SftB sessions was attendees' reactions, or rather non-reactions, to unconventional behaviour, demarcating an ethos of horizontal inclusion, but also providing relief for

attendees from having to conform to normative structures of society. Furthermore, the activity of singing allowed everyone in the group to participate and interact with each other beyond normative forms of communication. As such, this chapter contributes to work on embodiment and embodied communication, particularly in dementia contexts. Some notions of 'embodiment' assert that the self primarily resides in the body (Kontos 2006, 2012a, 2012b). As Kontos argues, we 'must embrace the idea that the body is a fundamental source of selfhood that does not derive its agency from a cognitive form of knowledge' (Kontos 2005: 1). This builds on Bourdieu's notion of 'habitus' and see the body as the site where personhood and agency are revealed. Here, the corporeal body is the site of a person's self-expression and interaction with its surroundings. As Pia Kontos argues, we 'must embrace the idea that the body is a fundamental source of selfhood that does not derive its agency from a cognitive form of knowledge' (Kontos 2005: 1). In this, the mind does not possess sole custody over one's ability to relate with the world: instead, persons are bodies in motion and the subtle, corporeal way one is in the world is an act of communication with it.

While Kontos' earlier work reconsiders the physical movements of a person with dementia as demonstrative of their agency, I wish to more explicitly push the boundaries of personhood beyond body and mind. I propose that personhood,

or a person's experience of being in the world, is not an individualised experience at all. Instead, this project is a social undertaking. Valid status as a thinking, feeling subject is not constructed by *either* the actions of a person with dementia or a carer; it instead relies on the relational back and forth with others. Personhood is thus not asserted by people with dementia themselves, which means that their own, outright agency in the process is lacking: it is a status bestowed, rather than something actively shaped by the person with the condition (Baldwin and Capstick 2007). Whereas Kontos et al. are interested in people with dementia as 'active partners in their own care', I have shown that in SftB sessions and in more intimate moments in people lives, my interlocutors were invested in people with dementia being partners in and through their care (and love) for others, as well.

In reiteration of one of Brijnath's findings, 'To discover the love that existed between people with dementia and their spouses was one of the most joyous findings of my ethnographic journey' (2014: 184). I too propose that love and connection are not obscure, abstract ideas but are the reasons so many carers and people with dementia grapple with and attempt to sidestep confusing temporalities. My informants crafted complex, creative and resourceful care strategies to keep their person with dementia anchored to a linear understanding of time, because being 'in time' is a powerful way to still 'be a person'. However,

SftB sessions demonstrate that when such temporal tactics failed, or held them back, they moved beyond time to continue searching for the 'person' in dementia. SftB is a liminal space that worked against constraints of time and the implications this had for what was, and what was not, deemed acceptable behaviour and communication – and impediments it created for meaningful connection.

While SftB sessions are joyful and fun, and offer a chance for people to reach out to one another and sing together, they also allude to the emotionally exhausting work that many families undertake, with remarkable perseverance, to find and craft moments of connection despite the progressive, encroaching effects of dementia. They also highlight why much of this work can be so painful, because in feeling that a person with dementia is being 'lost', so too do carers and people with dementia fear that their own histories, identities, and love are being lost as well.

Considering the heartbreak of 'losing' someone to dementia, and the relief of 'finding' them, investigating the methods and boundaries by which care is judged to be present shows that the terms of care can be negotiated to include love on its own terms. Foundationally, we see what care *does*. Caring *makes* persons. It is the way by which the people with whom I worked recognised one other as a



someone 'still there'. In the context of dementia, recognising forms of 'embodied' care allowed both carers and persons with dementia to be 'there' for each other, to be kind to one another. As such, care is not a static term, but one that is renegotiated on the ground by those performing it.



## CONCLUSION

In the final stages of this thesis, the soundtrack of the film *Interstellar* became my constant companion. I set it on repeat, finding the cyclical nature of Hans Zimmer's 96-minute loop soothing and just able to drown out the soft chatter of my officemates. The soundtrack is orchestral, with sweeping crescendos from church organs, chorale movements resembling the sounds of wind and speed, and in some tracks, the rhythmic ticking of a clock. *Interstellar* is a science fiction film about general relativity and its implications for the nature of time, its seeming unreality but enduring existence as a structure that is not static, but that bends and warps according to the shifting gravities of different spaces. Time is thus experienced differently by different characters in the film simultaneously, depending on where they are, and when the characters last departed from each other. The film follows a group of people seeking to navigate the temporal eddies

of a black hole and the temporal landscapes of different worlds to find a planet which humans can inhabit, following the slow demise of Earth. The heart of the film resides in the ways its characters craft connections across and through these differing temporalities and space. The consequences of falling out of temporal sync with loved ones is illustrated in the characters' painful grief. It is also evident in characters' vacillation between confusion and anger at feeling left behind or abandoned, and wondering if those who left Earth are still alive, still out there. A drive to connect and sustain life motivates the individual and collective efforts of the characters. The group that leaves Earth starts their journey in search of more hospitable planets for human life, and over the course of the film, they pivot their attentions and destinations to individuals whom they love – a daughter left behind, a lover on even more remote galactic shores. Once every cyclical repeat of the album, the cast members of the film read out a poem by Dylan Thomas (1953). When this track played, I paused to contemplate the tremendous undertakings of my interlocutors. The first stanza reads:

Do not go gentle into that good night,  
Old age should burn and rave at close of day;  
Rage, rage against the dying of the light.

\* \* \*

It might seem strange to open with a discussion about science-fiction story-telling in this concluding section of a thesis about the very real and everyday reality of Londoners living with dementia or caring for a relative with dementia. I did not discuss science fiction novels or films more than a few times with people in my field site, only touching on references to Star Trek or a shared admiration for the worlds crafted by Ursula le Guin in passing small-talk. However, I suggest that parallels emerge between such fictional narratives that unabashedly explore uncommon structures of time, and the experiences of my informants as described in preceding chapters. Akin to the characters in *Interstellar*, the people with whom I worked also sought to make sense of time as a concept and their lived experiences through the temporalities of past, present and future. They too worked to hold on to and adjust to the spatial-temporal rhythms of their lives as dementia progressively complicated all their endeavours to 'live well with dementia' and care for it.

In contrast to the science fiction epic, my interlocutors did not attempt to save the fate of humanity. Or is this entirely true? Carers and people with dementia created imaginative strategies in response to emerging difficulties of remaining orientated to the 'here and now', and to fears about 'losing' their relative, or

themselves, to dementia. If we consider personhood in the language of those who attended Alzheimer's Society support groups and service settings, as a measure or indication that a person is 'still there', I suggest that their everyday efforts to sustain personhood is indeed a heroic mission for human life. Importantly, this is life not solely defined by biomedical criteria, but informed by the notion that one can be 'still alive, but not there anymore'. The strategies described in this thesis account most for the *social death* faced by people with dementia, and also by familial carers who take on primary caring responsibilities. Such strategies consider what is at stake when one's ability to 'sort oneself out' and 'stay connected' to kin becomes increasingly complicated by the progression of this condition, underscoring personhood as a careful, interdependent balance between individuality and relationality. The preceding chapters have illustrated how this tension of Western personhood was negotiated across the temporal and spatial landscapes of my informants' everyday lives. My informants' discussions position care as a collection of practices that aim to support a person's needs so that they can remain 'still there', as well as a type of *relation* whose very enactment is a lighthouse signalling one's enduring 'there-ness'.

My first chapter was concerned with the importance of narrative in people's attempts to make sense of their experiences in the midst of dementia, building on other medical anthropological work on illness narratives. I showed that this

approach is learned through support group conventions in which members 'plot' one another on a timeline of dementia progression and 'map' one another within a network of support. Carers and people with dementia learn to organise their experiences into linear, chronological structures in support group settings, indicating that normative structures of time are those considered most coherent. Considering the importance of linear, chronological structures in normative narrative styles, my first chapter serves as a kind of preface to a thesis that has been organised around examinations of the past, the present, the future, and the liminal spaces 'beyond time' of my informants' lives.

Chapter 2 illustrated how carers and people with dementia engage with the past differently, but how ultimately, both groups use the past to establish a person with dementia's identity through biographical anecdotes. Carers search for the 'beginning' of dementia and learn to re-label past odd behaviour as 'the dementia' and not as representative of 'his old self' or who a person with dementia 'really is'. Alongside this process, carers also learn to label themselves as 'carers' in support group settings through anecdotes about growing care needs, verifying their transition into this role. Those living with dementia also used the past as a chronologically structured source of identity, but their engagement with the past is much less dementia-focused. Conversations instead centre on the back-and-forth exchange of biographical anecdotes, and identity is a project of

retrospection in which the past is positioned as a source of data about family life, accomplishments and capabilities. Among carers and people with dementia alike, who a person with dementia is and was, is constructed as an independent subject not intrinsically linked with dementia. In this, the significance of historical and present accounts as socially embedded and distinct individuals emerges.

I next explored specific kinds of strategies that carers and people with dementia devised to maintain orientation to the 'here and now', in response to the temporal and spatial disorientation which many people with dementia experience as their illness progresses. The entwining of time and space (Munn 1992) in determinations of 'what you're meant to be doing, when' became clear. The chapter explored being disorientated to the home, and to problems with getting lost in, or navigating the outside world. I showed that forgetting the temporal rhythms, historical familial routines, and spatial structure of the home has implications for kinship relations and for the house as a tool of kinship reorientation. The importance of control over its boundaries (Buch 2010, 2013, 2015) emerges in conceptualisations of the home as a site of safety, as well as my informants' resolve to find ways to 'still get out' and support others to get out. Going out enables people to mitigate their social isolation, continue to engage in activities constitutive of their identity outside the carer/cared-for dichotomy, and to re-balance the tension between independence and dependency in these



relationships. Achieving these aims raised ethical issues and relational implications in tracking, surveillance, and requesting help. These strategies highlighted that by doing the right thing, at the right time, in the right place, a person with dementia can remain their 'own person' who can 'still' reach out and connect to others.

Chapter Four examined my informants' engagement with the future as an uncertain temporal landscape which they felt they could not, and did not want to plan for in concrete ways. Focussing primarily on bureaucratic processes and legal documents such as Medical Directives and Power of Attorney documents, I argued that these processes are often seen to safeguard the medical and financial safety of a person with dementia and their family, without having to make specific contingency plans for the myriad challenges that could arise as dementia progresses. These processes were fraught with problems and could cause tense and resentful relations within families and between families and the state. The diligence of families' efforts to 'get them sorted' signal commitments to preserve their person with dementia's wishes and opinions about their own future into the future, and ways people with dementia themselves work to make their wishes clear. This would ensure that a person with dementia's enduring individuality is sustained, and illustrates that independence and autonomy are valued and relationally constructed projects.

The final chapter of my thesis stood in apparent opposition to those preceding it. I described and analysed Singing for the Brain sessions, during which it appears that attendees are able to move beyond the confines of conventional, linear time. I suggested that the set-up of these sessions create a liminal space through social equity, collective singing and participatory reminiscence, building on Turner's conceptions of liminality and *communitas* (1956). What becomes paramount to the sociality in these spaces is recognition of participants' willingness to *partake* in singing and conviviality. This space 'beyond time' makes use of memory not as an activity of accurate recall but instead as an emotive landscape across which both people with dementia and carers could actively seek connection with one another. The intrinsic overlap between individuality and relationality came into view, as well as the tenderness and affection between carers and their person with dementia, echoing other, more intimate moments of their lives. I showed that in spaces that allow for chronologically untethered memory and communication, people with dementia are able to be seen as persons who are 'still there.'

Returning to the *Interstellar* metaphor at the start of this chapter, my material has aimed to show that my interlocutors are similarly intrepid pioneers, navigating new regions of time and space. In spite of concrete biomedical understandings and treatments, dementia is largely unknown territory, except to those who have

'been there' before. It would seem that one cannot prepare for a 'journey with dementia', but that the efforts made by people in my fieldsite are evidence of the empirical knowledge and expertise to be gained by coming together with those in similar circumstances. This thesis thus offers insight into these support group spaces, in which carers and people with dementia devised strategies and pooled support in ways that allowed them to 'manage, despite it all'. And much like the protagonists in a sci-fi film about the demise of Earth and humankind, my informants' journeys into these new terrains were not ones chosen, but demanded of them by the reality at hand. The people with whom I worked who were living with dementia had no choice, it came upon most of them 'as a surprise'. Equally, those who cared for a relative with dementia assured me that 'there was no question' that they would heed the moral duty to care for kin (McKinley 2001; Faubion 2001; Sahlins 2011).

Navigating the landscape of dementia and providing dementia care is difficult, exhausting, and fraught with confusion and ethical dilemmas, as preceding chapters have shown. If 'dealing with' dementia is not a choice then, what motivates my interlocutors' particular approaches to dementia? What is at stake if one does not approach it in particular ways? What constitutes 'living well' or the 'good life' in dementia?

The answer it would seem resides in the questions themselves – living and life are at stake in contexts of dementia. The breathing, heart-beating alive-ness of a person matters, yes, but also all that constitutes a life: one's memories, one's connection to people and place, a sense of self and identity, one's current and past occupations. What matters is doing these things both alone, as well as with people with whom connections are made meaningful as a result.

A theoretical aim of this thesis has been to contribute to Janet Carsten's and Marilyn Strathern's discussions about what makes a person in Western contexts. I suggest that in exploring contexts of dementia in London in which people are described as 'lost' and 'not there' as the disease progresses, we gain unique understanding of what exactly must be lost in order to threaten personhood. The importance of autonomy, particularly in contexts of care, has 'typecast ['the West'] as a place/time where people make individual choices, while 'the Others' are said to be embedded in their communities' (Mol 2008: 142). Carsten, in response to Strathern's foregrounding of individuality in Western persons, proposes 'a notion of personhood where kinship is not simply added to bounded individuality (1992), but one where kin relations are perceived as intrinsic to the self' (Carsten 2004: 107). This thesis corroborates claims that considerations of Western persons'

relationality are needed. I have argued that remaining socially embedded in families and within wider social networks is one of my informants' primary aims. For instance, when people spoke about 'who I am', they described families raised, and the configurations of their current families. Carers often pointed to the first instances when their relative with dementia 'acted strangely' to a member of their family as the 'start of it [dementia]'. Further, I showed that people worked very hard to find ways to keep someone orientated to the 'here and now' so that they could continue to do meaningful things together. Spatial and temporal disorientation was often most painful and frightening not because it was necessarily a sign of cognitive diminishment, but because of the risks it posed to remaining in sync with others and remembering the 'thick relations' (Margalit 2002: 7) of one's kinship and home. Disorientation could threaten relatedness between people. Indeed, this impending risk was often the reason that people avoided thinking about the future in too much specificity: carers feared a future in which they would be alone, and people with dementia avoided thinking about the ways they would be 'just doolally' around kin. People are also wary of the shift in families' power dynamics that could result from tracking and surveillance others' moments, or pursuing powers of attorney or medical directives, and these processes even affected my people's relationship to the state. These fears of losing a sense of relatedness or relationships becoming unbalanced underpinned

the set-up of StfB sessions where people sought social equality and connection, and a shared participation in the back-and-forth of relationality. It is clear that people were invested in the shared, constitutive power of care to maintain and forge kinship and relatedness between people, despite threats dementia might create.

The significance of sociality and relatedness does not undermine the importance of individuality in people's reckonings of their self, their identity and their status as social subjects. Indeed, the importance of the distinctions of one's self from others and from the phenomenon of dementia are clear in my interlocutors' engagements with the challenges of dementia. Recall my first chapter's discussion of the importance of narratives in making sense of a one's experience. My informants, particularly carers, were all speaking about dementia: however it was well understood that each carer and each person with dementia had a unique tale to tell and live in the context of this illness. These unique narratives were shared in support groups as biographies – they were owned by individuals and likewise gave insight into a particular individual. This attention to the individual can be traced in subsequent chapters as well. The usefulness of the past emerged as a store of memories that could be re-evaluated to differentiate a person with dementia from their dementia, staking out behaviours that 'are him, and other

times when it's the dementia.' Both carers and people with dementia also sought to 'get out of the house' and 'be on my own' to pursue personal hobbies and routines. The dangers of the outside world, beyond the safe and relational space of home, were tackled because 'being stuck at home' often posed a greater threat to a sense of self and feelings that 'I can sort myself out' than did getting lost on the way to an appointment. Similarly, my informants sought ways to help people with dementia remain in their home, in line with common views that ageing-in-place is best (Buch 2015; Johansson et al. 2014). This is because as a site of kinship, control over this domain was indicative of one's capability to 'manage on my own' and not being 'too far along' a timeline of dementia progression. Likewise, control and decision-making were implicated in power of attorney and medical directive processes, and while they ultimately indicated that capacity would be lost, their undertaking indicated the importance of having people's choices in care (Mol 2008) documented and heeded. Finally, SftB singing sessions were so successful and well loved, I suggest, because social equality was built through people's attention to individual particularities and preferences. When I, as a volunteer, delivered tea or musical instruments to specified and habitual preferences, people as individuals were seen, counted, and recognised. And while care has been shown to be a significant aspect of kinship, we see that practices of care also sought to separate, divide and individualise so that people could be remain social subjects.

The significance of shared stakes in care in contexts of dementia also extends beyond academic theorisations of personhood or relatedness. The Carers (Scotland) Act 2016 was passed not long after the Care Act (2014) in England. Among government policy staff, fellow analysis colleagues, and carers support stakeholders across Scotland, there is a clear awareness of carers' need for support, which I witnessed first-hand during my internship within the Health and Social Care Analysis Division of the Scottish Government, in which I prepared evidence reports to support policy and practice development for the implementation of the Carers (Scotland) 2016 Act. However, uncertainty about how the aims of a national policy and these needs might be met by understaffed, and budget-stretched Local Authorities were pervasive. My research has highlighted the damaging and frustrating effects which uneven and slow implementation of policies related to these Acts can have on preventing the alienation and precarity which carers face in the absence of promised support.

Furthermore, implementation guidance and 'best practices' were moving toward the inclusion of care recipients (living with any long-standing illness who receive significant informal support from familial carers). Implementation guidance suggested that procedures allow for them to take part in conversations and have



a measure of authority about support packages put in place for carers, particularly those having to do with respite/replacement care that would directly affect them. However, no clear guidelines underpinned this shared decision-making model or who would have final say on how 'care packages' were devised or implemented, with unresolved confusion during the policy drafting stage about how to include people with dementia in these collaborative practices. The implications of my research point to how the ambiguity of these policies will have adverse implications in already complicated terrains of power, authority, and desires for connection in familial relationships, and particularly in relationships between carers and people living with dementia. On the one hand, they could serve to buoy the involvement and perspectives of those with dementia in such proceedings, signalling that support for one person (even if that person is the 'carer') is rarely an individual decision. I can foresee some of my carers relishing making this decision together, thereby assuaging guilt at 'taking over', and some of my informants with dementia wishing to agree to and endorse support for others. At the same time, I know some households where the conversations needed to draft a support plan would be avoided: conversations about care are already challenging, let alone with a bureaucratic stranger to whom desires to 'get a break from him' would need to be plainly articulated. Further, prevalent uncertainty related to assessing and supporting capacity and the authority of a

cared-for person with dementia could continue to obscure their stake in these planned collaborative models. My examination of lives lived with and alongside dementia point to the significance of clear, standardised knowledge and procedures relating to capacity and consent in bureaucratic settings, but also in clinical ones.

Indeed, many of my interlocutors – carers and people with dementia alike – mentioned that people with dementia are often ignored as contributing partners in care decisions by doctors and nurses who focus their attention on carers. This points the need for foundational, practical education models that familiarise medics with the ramifications that such clinical practices can have on the felt and perceived social death of those living with dementia, as well as how this can reduce the likelihood of some to seek out medical care for conditions besides dementia. Some programs like the ‘Time for Dementia’, delivered by Brighton and Sussex Medical School and the University of Surrey, aim to tackle these practices by ‘improve[ing] knowledge, attitudes and empathy towards people with dementia and their carers’ (NHS 2018) among health care students. The need for early-career education on this topic, but particularly the possible implications of uncertainty surrounding dementia capacity, is supported by my experience of teaching on an undergraduate course in a medical school which included ethics

case studies based on the possible implementation of diagnostic and treatment plans with people with possible 'memory problems' or recent dementia diagnoses. The nuances of capacity, ways to support capacity through collaborative family decisions, and variable tests for capacity was unfamiliar for a number of students. The pervading stereotype was that people with dementia lacked capacity, unless proven otherwise. My findings might serve to de-stabilise the notion of the cognitive frailty of all older people, and also notions that consent and capacity are always individual matters or should be, rather than a team effort for people with dementia and their families.

While I have staked out the ways in which my people in my fieldsite are relational and ways in which they are autonomous, the idea that these qualities are separate is inaccurate, but perhaps understandably challenging for policy makers and young students. My aim has been to show that *persons* are intrinsically relational and individual simultaneously, and that in contexts of dementia, *each is constitutive of the other*. I have also sought to show that projects of personhood are endeavours that work within and re-write normative temporal and spatial frameworks. Individuality and relationality fold into each other and tug on one other, much like dimensions of time and space do. In *Interstellar*, durations of time are stretched and contracted depending on one's distance to the mass of different

planets and astronomical phenomena. Modern physics theorises that gravitational pull bends time, rendering its passing a variable and contextual experience (Thorne 2014). Taking this as a metaphor, my interlocutors' experiences of time and space were bent and aligned by the gravitational pull of practices and places thick with relationality. Homes as sites of kinship were used to pull people back into orientation to the present. Likewise, a person with dementia who does not recognize a shared home and its relational history can render familiar places eerie for the cognitively well.

I turn to the topic of narrative structures of experience, in appreciation of story-telling approaches that digress from this linear path. This thesis has worked to highlight entanglements between memory and time. I have highlighted how dementia upends how memories are conventionally seen as accurate records of the past to be recalled, not episodes to be re-lived in confusing ways. The fundamental and basic cognitive difficulties people with dementia have with memory were often coupled with temporality in interesting ways. People with dementia may in fact remember events that have happened - a child being born, their parents dying, living in a particular flat - but these memories' validity as evidence that a person is *able to remember* is challenged when a memory cannot be accurately placed onto a conventional linear timeline of past, present, or future.

Further, memory and time are linked because this temporal confusion is seen as a symptom of dementia, and the degree to which a person with dementia is confused is a marker to determine 'how far along' they are on a linear progression of the disease. Similarly, people with dementia described their frustration and sense of helplessness at realizing a growing inability to order memories, such as knowing that they 'have something on' or 'somewhere [they're] meant to be' but cannot make sense of their diary or trust themselves to remember the way to an appointment. These experiences stand in sharp contrast to my informants' concerted efforts to present coherent, normatively chronological stories. The lives of carers and people with dementia are riddled with concerns about the *when* in which a person with dementia resides - which time-frame or set of memories they are inhabiting. In such a reckoning, people with dementia are family members who can become *lost* in time and in a confusion of a lifetime of memories whose chronological ordering is slowly unravelling. In response, families sought to stall the 'slow death of dementia' by anchoring them to conventional time. In such an approach, the link between orientation to the 'here and now' and personhood is emphasised. This emphasis shows that familial acceptance and/or rejection of temporal differences is at the heart of familial encounters with a person with dementia's dementia. It is also what is abandoned when such framings proved to be more destructive to moments of connection than useful to establishing

relationality. In these vacillations between normative temporal framings and their creative restructuring, we see the temporality is negotiated.

Consider the ways in which family members sought to stake out people's separateness in their relationships and to rebalance power and control between one another. Careful attention to who had the authority to decide the timing and place of people's activities became significant and ethically fraught. In seeking to avoid these types of control, people avoided relationships that slid into dependency, or in which carers and people with dementia became amalgams. Here the relational consequences of sharing *too much* time and space can be felt. For my interlocutors with dementia, in particular, this required creative and kind ways to 'get out of the house', refuse offers of help, and accept them when they deemed the peace of mind of family members was worth more than their own discomfort. It is important to note here how these approaches sought distance, but not a severing of relations. Time and space apart were considered 'good', but kinship was maintained through the offering and recognition of care (Taylor 2008). Safe separation was sought in relationship, and only made possible through it, and one must be a subject separate from others to form relationships to those others. Likewise, proper distance is needed so that one can recognise and reciprocate moments of care. When dementia created environs inhospitable

to continuing alive-ness, carers and people living with dementia pursued new ways to fashion a life in its aftermath. Thus, this thesis has also been about the constitutive, generative and creative qualities of care. As can be seen in many of my interlocutors' care strategies, they created distances of time and space between them so as to have a gap across which to reach back to one another.

What becomes clear is that personhood is not divisible into singular melodies of individuality or relationality, but lies in their orchestral harmony. What also becomes clear is that care is both constitutive of kinship, but can also threaten it. And like love, care 'doesn't just sit there, like a stone, it has to be made, like bread; remade all the time, made new' (Le Guin 1971: 159). Care is a practice, and thus, to exist and be generative, must be enacted, and re-enacted across time and space.

I close with the final words from the Dylan Thomas poem with which I opened this Conclusion. I do so to draw attention to the importance which my informants placed on certain elements in interactions between people with dementia and their family members.

And you, my father, there on the sad height,  
Curse, bless, me now with your fierce tears, I pray.  
Do not go gentle into that good night.  
Rage, rage against the dying of the light.

This thesis has demonstrated that the people with whom I worked navigated the eddies and landscapes of disjointed temporalities and space to connect to and to *be with* one another (Caldas and Berterö 2012). In the intimacies of *being with*, moments of communication were made still possible. The forms such communication took – be it a blessing or a curse – were often less important than the significance of a person with dementia contributing an original verse to the conversation *between* people. This is because one's fierce tears, their production as well others' witnessing of them - are moments of recognition and reciprocation of care. They simultaneously separate and entwine kin. I thus argue that my interlocutors' persistent, consistent, and dogged attempts to craft strategies that were always 'one step ahead of dementia' were efforts to 'not go gentle into that good night', but to 'rage, rage against the dying of the light'. Because in this light, families can see that their relative is 'still there'.



Perhaps someday we will discover that space and time  
are simpler than the human equation.

- Captain Jean-Luc Picard

*Star Trek: Next Generation, 1987*



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